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Models of Cancer Survivorship Care

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Preface

The Agency for Healthcare Research and Quality (AHRQ) conducts the Effective Health Care Program as part of its mission to organize knowledge and make it available to inform decisions about healthcare. As part of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Congress directed AHRQ to conduct and support research on the comparative outcomes, clinical effectiveness, and appropriateness of pharmaceuticals, devices, and healthcare services to meet the needs of Medicare, Medicaid, and the State Children's Health Insurance Program (SCHIP).

AHRQ has an established network of Evidence-based Practice Centers (EPCs) that produce Evidence Reports/Technology Assessments and Comparative Effectiveness Reviews to assist public- and private-sector organizations in their efforts to improve the quality of health care. Technical Briefs are the most recent addition to this body of knowledge.

A Technical Brief provides an overview of key issues related to a clinical intervention or health care service—for example, current indications for the intervention, relevant patient population and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Technical Briefs generally focus on interventions for which there are limited published data and too few completed protocol-driven studies to support definitive conclusions. The emphasis, therefore, is on providing an early objective description of the state of science, a potential framework for assessing the applications and implications of the new interventions, a summary of ongoing research, and information on future research needs.

Transparency and stakeholder input are essential to the Effective Health Care Program. Please visit the Web site (www.effectivehealthcare.ahrq.gov) to see draft research questions and reports or to join an e-mail list to learn about new program products and opportunities for input. Comparative Effectiveness Reviews will be updated regularly, while Technical Briefs will serve to inform new research development efforts.

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Structured Abstract

Background

The number of cancer survivors in the United States is projected to grow to 18 million by 2020. Few publications have described the process or outcomes of adult survivorship care models. The purpose of this Technical Brief is to describe existing and proposed models survivorship care for adults with cancer.

Methods

The Technical Brief integrates discussions with Key Informants and searches of published and gray literature.

Results

The literature review and Key Informants information consistently indicated considerable heterogeneity in models of survivorship care, model components, survivor populations included, and target outcomes. Models of survivorship care are highly individualized to the institution or setting where they are provided; broad-based "usual care" for survivors does not exist. Although competing considerations and incentives may in many instances lead oncologists to continue seeing cancer survivors, anticipated shortages in the oncology workforce may require other approaches such as the expanded use of physician extenders, shared care with primary care physicians, and patient navigators. Concerns associated with these alternatives include payment considerations, adequacy of training, and potential for fragmented care. Our systematic review of the literature for the Technical Brief identified nine empirical studies of survivorship care models, covering nurse-led, physician-led, survivorship plan, and individual/group counseling models. Future research is needed to explore the optimal timing of survivorship models (when to start and how long to continue), tailoring of models based on patient characteristics and risk factors, and key model outcomes.

Conclusions

The optimal nature, timing, intensity, format, and outcome of survivorship care models continue to be uncertain. Structural constraints, particularly associated with payment and collaborations between health care providers, may constrain innovation.

Background

The Increasing Population of Cancer Survivors and the Challenge of Transitioning From Cancer Treatment to Followup Care

As of January 2012, the United States had nearly 14 million cancer survivors, among whom 59 percent were ages 65 years or older.[1] The number of survivors is projected to grow to 18 million by 2020.[2] Survivors have unique physical, psychological, social, and spiritual health needs. The growing needs of survivors will occur as the oncology workforce is projected to experience substantial shortages.[3-5]

Relative to pediatric cancer survivors, adult survivors are understudied.[6] Further, their health care needs differ from those of pediatric survivors—for example, they have an increased risk for comorbidities, which presents unique care coordination of health care challenges. Consequently, this Technical Brief seeks to increase knowledge regarding survivorship care models for adult cancer survivors (age ≥19).

As described in the Institute of Medicine (IOM) report *From Cancer Care to Cancer Survivor: Lost in Transition*,[7] survivorship care (i.e., the delivery of health care services specifically designed for cancer survivors) ideally includes (1) prevention of new (primary) and recurrent cancers and of other late effects; (2) surveillance for recurrence or second cancers; (3) interventions for illnesses secondary to cancer and cancer treatment (including physical consequences of symptoms such as pain and fatigue), psychological distress experienced by cancer survivors and their caregivers, and concerns related to employment, insurance, and disability; and (4) coordination between specialists and primary care providers (PCPs)[*] to ensure that all the health needs of survivors are met.

Developing appropriate health care programs that provide needed supports and enhance outcomes for individuals with cancer following completion of acute (i.e., potentially curative) cancer treatment can be difficult. Current cancer survivorship care often involves medical oncologists following survivors for prolonged periods of time after treatment ends, which may or may not represent the preferred model for cancer survivors or for oncologists. Barriers to optimal care for cancer survivors may include differing perspectives, lack of communication, or lack of clear expectations among PCPs and oncologists on their roles in delivering survivorship care.[8] These may result in inadequate care coordination, leading to the duplication or omission of prevention, detection, surveillance, or treatment services.[9] This fragmentation of care may have significant adverse consequences for cancer survivors, including delayed detection of recurrences, suboptimal identification of symptom causes and treatments, and worse outcomes including health-related quality of life. Furthermore, survivors may feel poorly informed regarding psychological, social, and sexual health issues[10] and their risk for recurrence of cancer[11] and may be dissatisfied with care following cancer treatment.[12] However, it is also reasonable to consider whether certain survivorship care models, by involving additional clinicians in the health care for an individual, may themselves lead to greater fragmentation of care and potential harms, especially if communication and coordination of care is not addressed among providers.

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[*] PCPs include physicians, nurse practitioners, and physician assistants.

The challenges associated with the transition of cancer survivors to followup care may be exacerbated by the concerns PCPs may have about their ability to deliver survivorship care,[8] the rapidly growing number of cancer survivors in the United States, the projected shortage of oncologists,[3,13] and possible changes related to the Affordable Care Act[14] (e.g., the development of Accountable Care Organizations may influence where and by whom cancer survivorship care is delivered[15]).

Models of Care Intended to Enhance Outcomes and Provide Supports Among Cancer Survivors

An initial challenge for this project was to define a "model" of cancer survivorship care. The term "model" is frequently used in the cancer survivorship literature but is rarely (if ever) defined. Research shows a general agreement that a model of survivorship care involves a broad and holistic approach to followup care for cancer survivors, addressing multiple needs. As discussed by Gilbert et al.,[16] while approaches vary, all models are directed toward the common goal of improving the quality of care provided to cancer survivors by delivering comprehensive, coordinated and tailored follow-up care.[16, p.435]

Multiple published studies examine the effectiveness of programs addressing a single need among cancer survivors, such as support or counseling for psychological distress.[17-40] We believe that a program addressing a single need would not be considered a model of survivorship care. Similarly, a program that involves a single service provided to cancer survivors, such as facilitating surveillance for cancer recurrence or the development of new cancers, would not be considered a survivorship care model. For this report, we have defined a model of survivorship care as ***a program for cancer survivors that addresses two or more different health care needs*** as a minimum threshold for a "model" of care.

In this report, we refer to model "components" as the four categories of survivorship care identified by the IOM report *From Cancer Patient to Cancer Survivor: Lost in Transition*: prevention, surveillance, intervention, and coordination. Within each of these categories are multiple health care needs experienced by cancer survivors. Further, multiple health care services may be provided to address each need. To clarify this terminology, consider a program designed to provide foot care for cancer survivors. This program could involve multiple health care services, including care from orthopedists to assess and potentially treat bone and joint abnormalities, podiatrists to diagnosis problems and potentially provide treatments including orthotics, and physical therapists to recommend exercises. However, all of these services focus on a single need: foot problems among cancer survivors. Despite this hypothetical program incorporating multiple health care providers and services, we would not consider this a model of survivorship care because it addresses only a single need.

It is unlikely that cancer survivorship care will have a "one-size-fits-all" model. Many factors may influence which model will be most effective for a given situation, such as the number and type of survivors being served; available health care providers, services, and resources; risk of recurrence and level of symptoms following cancer treatment; and patient preference regarding the type and source of survivorship care. Different models of survivorship care have been described; a subset of the characteristics of these models is discussed in the Guiding Questions (GQs) below. Types of survivorship care models include community-based shared-care models, academically based comprehensive survivor program models, nurse practitioner–led shared care, and multidisciplinary programs for high-risk populations.[41] These models are based on the providers delivering the care and the structure of the program or services being offered for

survivorship care. For example, an academically based program may be offered for specific disease groups while that may not be possible in other settings. Resources for survivors may be offered within a program or as separately available services within the community to address unmet needs. For example, a comprehensive survivorship program may offer exercise programs, or a smaller program may partner with a local YMCA to offer the LIVESTRONG℠ program for survivors.

According to a recent report on survivorship care from the American Society for Clinical Oncology, "Because no uniform standards for the care of survivors exist, significant efforts are required to understand the needs of survivors and to develop models of comprehensive, coordinated care that meet those needs."[42, p.2] As discussed in this American Society for Clinical Oncology report, additional research is needed to "expand the evidence base required to define optimal care delivery, including the type or components of care delivered, the manner in which that care is delivered and by whom, and the efficacy of the various models of care."[42, p.2]

A number of previous studies have described different models for delivering survivorship care and summarized research efforts in this area.[7,42,43] However, few publications have described the process or outcomes of survivorship care models. Therefore, the purpose of this Technical Brief is to describe different existing and proposed models of and services for survivorship care to promote understanding of the differences in care delivery and survivor outcomes associated with these models. The Technical Brief will also present information on studies of survivorship care models and their outcomes, explore the breadth of information available on these models and gaps in this literature, discuss potential issues that are important to key stakeholders, and identify areas of future research needs.

Guiding Questions

The GQs and subquestions that we used to collect information from published studies and Key Informants (KIs) are listed below.

1. **Overview of cancer survivorship care**

- What are the different models of cancer survivorship care that have been most widely used?
- What are the components of cancer survivorship care?
- What is the nature of usual care for survivors of cancer?
- What are the potential advantages and disadvantages of these models, when compared with one another and with usual care?
- What are the potential safety issues and harms?

2. **Context in which cancer survivorship care is used**

- What information do patients, clinical care providers, or other decisionmakers receive about survivorship programs or components of those programs?
- How do models of care vary based on the following?
  - Setting
  - Organizational structure

    - Provider type and responsibilities of varying provider types in medical care for survivors, including providers involved in the patient transition from acute cancer treatment to ongoing survivorship
    - Payment considerations
    - Patient characteristics such as age, race/ethnicity, cancer type, stage of disease, and other risk-stratification issues
- What associated supportive care resources are commonly incorporated in or needed for survivorship care programs?
- How is risk stratification being (or could be) applied to cancer survivor programs?
- What kinds of resources (e.g., health information technology) are available or needed to share information among health care providers and with patients?
- What are important considerations for evaluating appropriate resource utilization, cost, quality of care, and outcomes for survivorship programs?
- How widely is survivorship care offered? For how long?
- What kinds of training and staffing are required? What modifications to current training and staffing are in development?

3. **Current evidence on cancer survivorship care**

- Characteristics of patients enrolled (age, race/ethnicity, cancer type, stage of disease)
- Type of survivorship model, if defined
- Setting
- Organizational structure of the health care entities involved in survivorship care and in the transition from acute care treatment to survivorship care
- Provider type
- Payment considerations
- Study design and size
- Comparator used in comparative studies
- Concurrent or previous treatments
- Length of followup
- Cost and resource utilization
- Outcomes measured
- Adverse events and unintended consequences of survivorship care

4. **Gaps in knowledge and future research needs**

- What are the key decisional uncertainties?
- What are the implications of the current level of diffusion and/or further diffusion of cancer survivorship care, given the current state of the evidence?
- Are there models of survivorship care that are planned but have yet to be implemented?
- What are the differences between existing models of survivorship care and new and emerging models of survivorship care?
- What are possible areas of future research?

Methods

A Technical Brief is a rapid research review that describes what is known and what is not known about new or emerging health care topic based on the current body of literature. Systematic reviews, in contrast, synthesize study results or assess the methodological quality of the studies identified and included in the search. A Technical Brief does not attempt to grade or rate the strength of the evidence of the literature. The purpose of a Technical Brief is to provide an overview of key issues related to the intervention such as current indications, relevant patient populations and subgroups of interest, outcomes measured, and contextual factors that may affect decisions regarding the intervention. Technical Briefs integrate discussions with Key Informants (KIs), a search of the gray literature, and a search of the published literature.

Discussions With KI

The KIs were particularly useful for shaping the Technical Brief because little empirical evidence exists about a gold standard model of survivorship care. The KIs contributed to understanding which components of the models are in current use and considered to be most effective across cancer types, where the models might fit into clinical care, and potential advantages or concerns related to developing and implementing these models. Specifically, responses to GQs 1, 2, and 4 are based largely on KI discussions.

The 10 KIs that the Evidence-based Practice Center (EPC) interviewed represented various fields of expertise related to cancer survivorship: patient advocacy (n=2), policy (n=3), management and administration (n=2), financing and reimbursement (n=1), primary care (n=1), and research (n=4); some KIs represented multiple fields of expertise.

Gray Literature Search

GQs 1, 2, and 4 listed above primarily relied on information from published narrative reviews and information in the gray literature. The EPC used the gray literature to identify additional model components that are in piloting stages or not yet fully implemented. The EPC identified 96 nonduplicated citations from the gray literature search.

Published Literature Search

Criteria for Inclusion/Exclusion of Studies in the Review

Table 1 lists the inclusion and exclusion criteria in our protocol. Although survivorship encompasses varying stages of the cancer survivor's experience, this report only includes studies of individuals who completed active treatment. Our preliminary inclusion criteria did not constrain the included studies based on the comprehensiveness of the services offered. We included all studies that offered at least one of the four core Institute of Medicine (IOM) survivorship care components. During the literature review process, we identified numerous studies that addressed single needs of patients following cancer treatment. Our conversations with the KIs and our review of the literature in parallel led us to map our inclusion more closely to the construct of care coordination underlying models of survivorship care. We included studies that addressed multiple patient needs of one patient and excluded those that addressed single patient needs of one patient regardless of whether single or multiple provider service(s) were offered. We further clarified categories of interventions as serving the following:

1. Multiple patient needs and multiple providers' services *or* multiple patients' needs and a single provider service. We included these studies for review.
2. Single patient's needs and multiple providers' services. (Nine studies were excluded as "single need-multiple provider.")[32-40]
3. Single patient need and single provider service. (Fifteen studies were excluded as "single need-single provider.")[17-31]

We added this construct to our inclusion criteria by requiring two or more service(s) for survivorship care within one or more of the four core IOM survivorship care components (prevention, coordination, surveillance, intervention) intended to facilitate survivors' experience.

Table 1. Eligibility criteria for survivorship care

Criterion	Inclusion	Exclusion
Population	• Ages 19 or older • Survivor of adult cancer (any cancer type) • Currently in remission	• Ages 18 or younger • Adult survivor of childhood cancer • In relapse at enrollment in a survivorship study • Individuals with metastatic cancer
Intervention	• Two or more service(s) for survivorship care within one or more of the four core IOM survivorship care components (prevention, coordination, surveillance, intervention) intended to facilitate survivors' experience • Formal referrals to service(s) that facilitate survivors' experiences	• Treatment with curative intent • Studies of a single service • Studies that provide information only on patient characteristics associated with using survivor services
Comparator	• Active comparison with other survivorship care models • Active comparison of components of survivorship care • Usual care • No comparator (for case series)	• None
Outcomes	• Any patient outcomes related to the survivorship care model • Intermediate patient health outcomes • Morbidity • Mortality • Quality of life • Satisfaction with care • Cost and resource utilization • Adverse events	• Outcomes attributable to the cancer treatment (except for adverse events and other long-term consequences potentially resulting from cancer treatment) • Outcomes among health care providers
Timing	• All timing	• None
Setting	• All care settings	• Acute care inpatient
Study design	• Systematic reviews • Randomized controlled trials • Nonrandomized controlled trials • Prospective and retrospective cohort studies • Case-control studies • Case series	• Case reports • Opinions • Commentaries • Nonsystematic reviews[a] • Letters to the editor with no primary data
Other	• English language	• Non-English language

[a] Nonsystematic reviews may be used to inform our responses on GQs 1, 2, and 4.

Abbreviation: IOM = Institute of Medicine

Searching for the Evidence

The EPC systematically searched, reviewed, and analyzed the available information for GQ 3. We then reviewed studies identified as being of potential relevance for GQ 3 and for potential relevance to the other GQs. To identify articles for this review, we conducted focused searches of PubMed, CINAHL, Cochrane Library, EMBASE, and the gray literature sources. The EPC scanned the reference lists of systematic reviews that are pertinent but do not meet inclusion criteria to identify studies that should be considered for this review to address GQ 1, 2, or 4 as background information. The EPC reviewed each study identified through these "hand-search" processes against the a priori inclusion and exclusion criteria described in Table 2.

Data Abstraction and Data Management

The EPC developed forms for the initial inclusion/exclusion process at the title/abstract and full-text review stages. Appendix B lists the sample forms used at both stages. The EPC used the forms to screen titles, abstracts, and full reviews and to gather information about study characteristics and the PICOTS (population, intervention, comparator, outcomes, timing, and setting) of each study.

Two trained members of the research team independently reviewed all titles and abstracts identified through the published and gray literature searches against our inclusion/exclusion criteria. Reviewers categorized the studies according to relevance by GQs. All studies relevant to GQ 3 marked for possible inclusion by either reviewer underwent full-text review. For studies relevant to GQ 3 without adequate information to determine inclusion or exclusion, the EPC retrieved the full text and then made the determination. The EPC tracked all results of the review in an EndNote® database (Thomson Reuters, New York, NY).

The EPC team retrieved and reviewed the full text of all studies relevant to GQ 3 included during the title/abstract review phase. Two trained members of the research team independently reviewed all studies relevant to GQ 3 for inclusion or exclusion on the basis of the eligibility criteria described earlier and considered the appropriateness of each study in this group for the other GQs. If both reviewers agreed that a study did not meet the eligibility criteria, the study was excluded. If the reviewers disagreed, conflicts were resolved by discussion and consensus or by consultation with a third member of the review team. The EPC team tracked all results in an EndNote database noting the reason that each excluded full-text publication did not satisfy the eligibility criteria. Appendix C provides a comprehensive list of such studies.

The EPC designed evidence table data abstraction forms to gather pertinent information from each article, including characteristics of study populations, interventions, comparators, outcomes, study designs, settings, and methods. For studies that met the inclusion criteria, the trained reviewers abstracted relevant information from each article into summary tables using the evidence table abstraction form. All data abstractions were reviewed for completeness and accuracy by a second member of the team. Appendix D includes complete evidence tables.

Data Synthesis

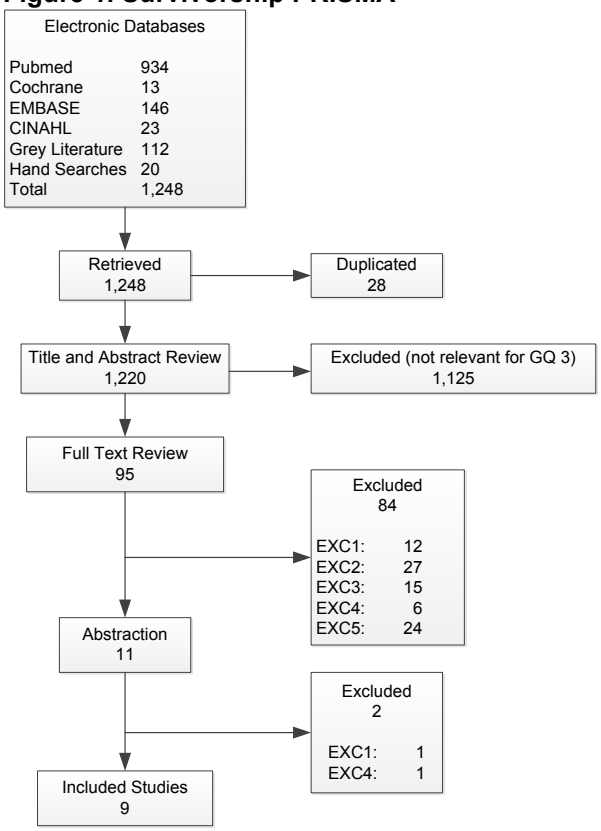
To be consistent with the purpose of the Technical Brief, the EPC did not conduct an analytic synthesis such as a meta-analysis but provides a summary of the evidence for each GQ in the following section. The EPC considered the models used, study design, analytic methods, and the similarities and differences of included patients according to sociodemographic factors (e.g., age) and classified type of cancer detailed in the Findings.

The EPC integrated data from the published literature with information from the gray literature and discussions with KIs. The responses to GQs 1, 2 and were primarily informed by information from discussions with KIs and secondarily by published literature and gray literature or nonsystematic published reviews. Responses to GQ 3 were primarily based on peer-reviewed, published literature and combined with information from the gray literature.

Findings

The findings from the literature search are presented in the order of the Guiding Questions (GQs) and qualitatively summarize findings from gray literature searches and interviews with KIs. For questions with empirical evidence or in-progress studies to inform the results, cross-cutting tables describe the state of evidence on study characteristics (number and types of study designs addressing each survivorship model or component), intervention characteristics, and types of outcomes planned or presented for each survivorship model. Figure 1 describes the number of studies at each stage of the literature search and review process that the Evidence-based Practice Center (EPC) identified for GQ 3 and the resulting studies for background (GQs 1, 2, and 4) included from this group. These studies describe models of survivorship care and are completed or in progress.

Figure 1. Survivorship PRISMA



GQ 1: Overview of Cancer Survivorship Care

Models of Cancer Survivorship Care

As discussed in the Background section, although the term "models" is frequently used for survivorship care programs, this term is rarely if ever defined. Similarly, although the cancer survivorship care literature identifies or describes a wide variety of models, no commonly accepted taxonomy exists. Authors have generally focused on the type of survivors for whom care is being provided, the setting of care, the type(s) of clinician providing care, or the purpose of the survivorship care program. Models categorized by the type of survivor receiving care are described as disease-specific vs. general.[32,44] McCabe and Jacobs[44] describe a breast cancer-specific model as a means of meeting the needs of breast cancer survivors posttreatment. In this disease-specific model, directly after treatment ends, oncology nurses and physicians identify issues that survivors may experience (e.g., lymphedema, fatigue, psychological distress) and provide an organized set of services to address these issues. In contrast, for a general survivorship model, nurse practitioners, oncologists, and/or primary care providers (PCPs) typically collaborate to provide care to survivors of all types of cancers. The general survivorship model may include a treatment summary, a care plan, and/or referrals for services not provided by the survivorship program.

Models categorized by setting of care generally focus on the difference between those based in "separate" survivorship clinics vs. "integrative" models.[32,44] Survivorship clinic models involve care for cancer survivors provided in a setting that is separate from that where cancer treatment care was received. The setting for some survivorship clinic models may be referred to as a "consultative clinic" when a survivor is referred for a single survivorship visit. In contrast, as the name suggests, integrative models integrate survivorship care into broader oncology practice. In the integrated model, a team of health care providers may oversee survivorship care.

Models that are classified based on type(s) of clinicians providing care include physician-led models, nurse (or nurse practitioner)-led models, and models led by other types of health care providers. In addition, models may be led by a care team, with different types of clinicians taking the lead for different aspects of survivorship care. In section GQ 3 of this report (below), we describe and compare clinician-led models in more detail.

Finally, survivorship care models may be classified based on the purpose of the survivorship care program. An example is the "transition to primary care" or "transition clinic" model.[32,44] As the name suggestions, the focus of this model is to transition cancer survivors away from care provided by oncologists and back to care provided by PCPs. This may involve a risk-based approach, where survivors are transitioned back to PCPs only when their risk for recurrence or late effects of cancer or cancer treatment is low. Another purposed-based classification is the multidisciplinary coordination models, which are characterized by clinicians such as nurse navigators coordinating care for survivors across multiple providers.[44,45] In other models, the main goal appears to be the development of a survivorship care plan (SCP) that can be provided to cancer survivors and potentially shared with their other health care providers (such as PCPs). Examples of SCP-focused models are described in section GQ 3 of this report (below).

The classifications for cancer survivorship care models described above are not exhaustive; other types of survivorship care models may exist. Further, this classification is not mutually exclusive. For example, separate survivorship clinic models can be disease specific or general and can be physician led or nurse led. The lack of a consistent and agreed-upon classification

schema for survivorship care models results in increased challenges for comparing structures, processes, and outcomes across different models.

In addition, the literature provides little information regarding which models are most widely used. One study identified several models of cancer survivorship care among eight LIVESTRONG Survivorship Centers of Excellence, including disease-specific clinics, separate survivorship clinics, and integrated models.[46] One systematic review listed disease-specific clinics, general survivorship clinics, consultative clinics, multidisciplinary clinics, integrated care, and transition to primary care models among the models examined.[44]

In response to an open-ended question about what models of survivorship care have been widely used, the four KIs commenting on this question echoed the literature: In sum, they suggested a wide variety of models exist, but little information regarding which models are most widely used is available. One KI listed three models in his organization: a group-visit model for breast cancer survivors; a model involving an individual, one-time consultation with multiple providers for breast cancer survivors; and a model involving an individual, one-time consultation with multiple providers for adult survivors of childhood cancers. Another KI described a model in which care continues to be provided by an oncologist after treatment is complete and a model that involves an oncology medical home. Two other KIs indicated that no single or most widely used model of cancer survivorship care exists. In practice, they said, "models" of survivorship care are highly individualized: the kind of survivorship care that a survivor receives depends on the relationship between the provider and the survivor, as well as the survivor's risk associated with the disease (e.g., late toxicity).

Components of Cancer Survivorship Care

The Institute of Medicine (IOM) identified four essential components of cancer survivorship care: prevention, coordination, surveillance, and intervention.[7] In later sections of this report, we evaluate the extent to which empirical studies of survivorship care address these components.

Several observational studies that assess the relationship between models of cancer survivorship care interventions and processes of care and/or outcomes contribute to this literature by describing components of the models.[28,33,45,47,48] For example, one study assessed a model that involved a contract discharging survivors from an oncology clinic during a final visit.[33] Other studies assessed interventions targeted at coordination and prevention such as SCPs, end-of-treatment consultation, followup phone calls, exercise, counseling, and informational resources.[28,47,48] KIs emphasized surveillance and intervention components as being critical to survivorship care. Specifically, one KI noted that care plans were essential in implementing ongoing surveillance and monitoring of cancer survivors. For the intervention component, KIs also noted that interventions should address both the patients' physical and emotional needs, address the needs of family caregivers and prevention efforts, and be designed based on patients' risk assessment for recurrence and late effects. Some KIs also highlighted the importance of offering these components across the continuum of care and ensuring that patient empowerment is an underlying principle for each.

Nature of Current Clinical Practice for Survivors of Cancer

One observational study assessed cancer survivorship care in LIVESTRONG Survivorship Center of Excellence sites.[49] Self-reports of survivors ages 18 to 39 indicated that 71 percent attended an oncology survivorship clinic at the time of the survey, 48 percent reported that they did not have a treatment summary, and 55 percent reported that they had not received a SCP.

Seventy percent reported that an oncologist was the "most important" provider for test and treatment decisions; 10 percent reported receiving care in a "shared-care model" that involved both PCPs and oncologists.

The EPC identified seven guidelines.[34,42,50-54] The guidelines varied in type of cancer (breast, prostate, lung, and colorectal) and the components of cancer survivorship care that they addressed All addressed surveillance (i.e., routine followup care and screening), but only three[51,54,55] addressed prevention (e.g., proper nutrition and increased physical activity). Similarly, only three[42,53,54] addressed coordination. For example, one guideline[54] recommended coordination between PCPs and oncologists (i.e., shared- care model). Two[42,54] guidelines recommended interventions such as the expansion of evidence-based research; survivorship education for health professionals, patients, and their caregivers; and the use of SCPs.

The themes that emerged from the KI interviews suggest that current clinical practice for cancer survivors reflects the variation across guidelines. First, KIs described current clinical practice as disjointed, uncoordinated, and highly varied. KIs described resources for cancer survivors including psychosocial support, assistance returning to the workforce, surveillance efforts, and prevention initiatives; however, KIs emphasized that these resources were uncoordinated and varied across cancer survivors and within cancer programs. One consequence of this lack of coordination that KIs identified was lack of clarity about roles and responsibilities among providers of cancer survivorship care. A consequence of this lack of clarity about roles is the over- and underuse of surveillance testing. One KI summarized the theme of lack of coordination: "…[Current clinical practice] is still quite a hodgepodge although there is a lot of discussion about a more formal plan about how individuals should be followed once they complete treatment and it's focused on recurrence. Also, the duration of followup is also very haphazard; there is no risk-based approach for how long people need to be followed by their oncologists. The testing that is done as part of this surveillance for recurrence is also extremely variable and physician-dependent. In part, because there hasn't been guidance or guidelines developed until recently. There is beginning to be some, not evidence-based, but consensus-based ways of approaching this. Many people are trying various models that fit into their own practice settings. The models are being utilized and implemented based on feasibility of staff and finances, but not any outcome data."

A second theme that emerged from KI interviews related to challenges to coordinating care for cancer survivors. Challenges included providers' lack of confidence in providing survivorship care, financial incentives that discouraged survivorship care coordination, and ineffective integration of survivorship care into cancer treatment. One KI described the influence of the Centers for Medicare & Medicaid Services' (CMS') decisions on cancer survivorship care. This KI noted that unless CMS includes a service in a benefit category, the service will not be covered. Many features of optimal cancer survivorship care are not covered currently. For example, providers are not reimbursed for counseling or time spent on developing a survivorship care plan. Another KI suggested that care coordination is obstructed by lack of integration into cancer treatment; consequently, many providers and survivors view survivorship care as an optional supplement to treatment, not a cohesive stage of their care.

A third theme relates to new care modalities in cancer survivorship care, such as patient navigation, consultative models, survivorship medical homes, and SCPs that include distress screening and screening to prevent or detect new cancers or other chronic diseases and to increase knowledge of genetic syndromes associated with cancer. These approaches have emerged to address the variation and lack of coordination that is characteristic of current clinical

practices for cancer survivors. Some KIs acknowledged that uptake of these approaches has been poor.

Potential Disadvantages and Harms of Survivorship Care Models

Potential advantages and disadvantages of cancer survivorship care models compared with one another were not described in the literature or by KIs.

As described above, KIs described a lack of comprehensiveness and coordination among resources for cancer survivors. Many of the advantages of new models of cancer survivorship care address concerns related to current clinical practice. For example, some models address needs that are often not addressed in current clinical practice, such as integration back into the workforce and psychosocial issues, and they aim to prevent and detect new cancers or other chronic diseases more effectively and efficiently than current clinical practice.

KIs identified several disadvantages associated with new models of cancer survivorship care. Some disadvantages were logistical. Two KIs suggested that current financial regulations disincentivize new models. One KI suggested that oncologists have financial incentives to continue to care for cancer survivors. Another indicated that CMS does not cover services that might be included in new models. Another logistical disadvantage of new models was their lack of integration into existing models of cancer treatment: One KI suggested that providers and survivors view survivorship care as an optional supplement to treatment, not as a cohesive stage of their care. Consequently, the KI suggested that cancer survivors may self-select out of new models of survivorship care.

A second category of disadvantages is related to the shift in practice patterns or clinical knowledge that may be needed for providers to accept new cancer survivorship care models. Two KIs suggested that some PCPs, who have a central role in many new models, are not confident in their ability to provide cancer survivorship care. Likewise, some oncologists question PCPs' ability to provide cancer survivorship care. Another KI suggested that providers of usual care for cancer survivors may feel threatened by new models.

A third disadvantage of new models that KIs identified was their low levels of uptake, outside of early adopters.

KIs identified the following potential safety issues or harms associated with cancer survivorship care models: insufficient surveillance, intervention, and coordination; the risk of fragmentation of care with alternative approaches (e.g., models such as shared care that are intended to improve care coordination could result in care fragmentation if roles are not clearly delineated); and the risks of poorly managed latent effects due to the lack of adequate followup and coordination with current models of care.

GQ 2: Context in Which Cancer Survivorship Care Is Used

Choice of and Information on Survivorship Programs

Although studies describe information needs among survivors, the EPC found no studies that commented on whether patients and clinical care providers are informed of multiple programs and how they choose among survivorship care programs. The little information available suggests that patients are offered no information or offered a single choice. One mixed-methods study including a survey and focus groups of survivors of endometrial cancer in Canada found that only 23 percent of survivors had received some sort of treatment summary.[56]

Input from KIs provided context for our inability to find studies on how patients and providers access information on and choose among survivorship care programs. KIs observed that patients do not really have choices regarding survivorship programs. First, their clinical providers may be unaware of services or unable or unwilling to provide services even if patients should request it, and even when they do receive services, usually the patient's insurance decides where they go. If insurance does not make the decision, one KI suggested that the family decides, not the patient themselves. Another KI offered the example of adult children selecting care for older patients based on their own relationship with a hospital or a provider rather than the patient's relationship.

Sources of Variation in Survivorship Care

Organizational Structure and Setting

Although reviews of models of care noted settings in which these models had been implemented,[44] no study described how models might vary based on organization or setting. KIs offered anecdotal insights regarding potential variations by organization and setting.

One KI noted that "institutional flavors" of survivorship care exist. One KI suggested that institutional variation is likely to be much greater than provider-level variation. He observed that large institutions have their own way of doing things, and as a dispassionate observer, he was not convinced that any one approach was evidence based.

Regarding setting, one KI felt that community-based and online providers of survivorship-related resources tend to be related to wellness. The mismatch between resources and needs also emerged in KI interviews. Settings in rural areas have fewer resources but great need, and the onus in such settings gets shifted onto the patient.

Provider Responsibilities and Type

KIs noted that substantial provider-to-provider variability in responsibilities exists, in part because the evidence base providing direction on what to do (as opposed to what not to do such as ordering unnecessary scans) is weak.

Regarding provider type, KIs echoed concerns in the literature about the impending shortage in the oncology workforce to address the needs of growing numbers of survivors,[3,13] although, as one KI noted, community oncologists like to continue to see survivors because "it keeps them sane."

The pending workforce shortage in oncology points to the need for, as KIs noted, "physician extenders" (i.e., nurse practitioners and physician assistants). KIs noted that patients view nurse practitioners as extensions of the oncologist and trust them. In the view of one KI, nurse practitioners may be more open to following an evidence-based approach than oncologists when interacting with patients and still possess the subject matter knowledge to allow them to be effective. Regarding patient preferences for provider roles in survivorship, a survey of adult cancer survivors identified from hospital databases and clinic lists at a regional cancer center in Sheffield, United Kingdom, suggested that regardless of cancer type, cancer survivors preferred consultant-led care to nurse-led, telephone, or general practitioner-led care.[57] A possible explanation for the stated preferences for consultants might be patients' preference for continuity of care and the value that survivors place on their relationship with specialists who treated their cancer.[58] Although survivors were receptive to the idea of greater involvement of their general practitioner in followup care in shared care with an oncologist[58] as well as nurse-led care,[58,59]

they noted concerns about lack of specialized training. Additionally, they expressed some concerns about reluctance on the part of general practitioners to take on survivorship care. A structured review of followup of breast cancer patients found evidence that general practitioner-led care is as effective as specialist care, but this review was evaluating empirical evidence of patients attending a routine followup service after treatment rather than broader survivorship care services.[60]

Some KIs suggested that a shared-care model offers the greatest promise in common instances where community PCPs feel ill equipped to assume total care for cancer survivors. They noted that expecting PCPs to remember recommendations for all types of cancers is not realistic. Other KIs struck a note of caution regarding the shared-care model, noting the risk of fragmentation of care, lack of clarity about roles and responsibilities, and unnecessary tests. One study of a convenience sample of young adult cancer survivors recruited through the LIVESTRONG Survivorship Centers of Excellence Network, suggests modest anticipated changes in provider types. The majority (70 percent) of the convenience sample considered their oncologist as the doctor in charge of the most important treatment or test decisions. This sample included patients with very variable median time since diagnosis from 7 to 328 months. As many as 69 percent anticipated continuing to rely on their oncologist for the next 6 months. Only 10 percent relied on a shared-care model as the approach addressing the most important treatment or test decisions, and the proportion expecting to continue to rely on shared care in the upcoming 6 months declined to 5 percent. The proportion relying on a PCP at the time of the survey was 4 percent; 10 percent anticipated relying on PCPs in the upcoming 6 months. Multivariate analysis suggested that the model of care was not a significant predictor of the level of confidence young adults had in managing survivorship care.[49]

Payment Considerations

A fundamental constraint to financial feasibility of offering survivorship care is the cost of preparing treatment summaries and survivorship care plans.[46] In addition to the issue of reimbursement for SCPs, coverage for clinical services can be a problem.[46] Several KIs, including clinicians and patient advocates, also noted the difficulty, from the provider's perspective, in providing a financially sustainable model of care. In some cases, the reimbursement structure is such that oncologists may express interest in providing survivorship care, but they "always say they don't get paid for it and it takes a lot of time." Therefore, to do proper survivorship care or to transition the patient is difficult financially. One KI recounted an instance of a model of an oncology medical home outside of Pennsylvania, which was very effective at reducing emergency room visits, but almost caused the practice to go out of business by reducing visits.

KI interviews also suggested some differences in the perception of the willingness of insurance companies to pay for such care. Some KIs suggested that most insurance (with the exclusion of high-deductible insurance) would typically cover such services, but one clinician suggested that insurers were unlikely "to step up because there's nothing in it for them. There's no money involved."

Nonetheless, KIs were in broad agreement that survivorship care services were not expensive. Several KIs focused on the enormous costs of treatment relative to survivorship care, with one KI asking, "Why do we dump all this money into treatment if we let patients fade out at end?"

Patient Characteristics Such as Age, Race/Ethnicity, and Cancer Type and Stage

Available literature and KIs suggest that the type of cancer may influence interest in and variation in survivorship care models. Following the launch of an Internet-based tool for the creation of SCPs, an evaluation of users found that breast cancer represented the most commonly reported primary cancer diagnosis (over 45 percent), followed by hematologic, gastrointestinal, gynecologic, and genitourinary malignancies.[61,62] Likewise, the type of cancer may influence interest in specific services. In focus groups of self-selected participants, the breast cancer focus group in particular expressed a need for more spiritual support during active treatment and followup care.[59]

KIs also identified age, race, socioeconomic status, and insurance status as key variables that might influence survivorship care needs. In a convenience sample of young adult cancer survivors recruited through the LIVESTRONG Survivorship Centers of Excellence Network, multivariate analysis showed that minority racial status and lacking a followup SCP were associated with greater odds of low confidence in managing survivorship care.[49] A survey of cancer survivors identified through the Pennsylvania Cancer Registry found that age, number of comorbidities, income, stage of disease, and the interaction between age and number of comorbidities predicted the level of unmet need.[63]

Associated Supportive Care Resources Needed in Survivorship Care Programs

The literature on supportive care needs varies by the type of cancer survivors (younger adult,[57] cancer survivors with preexisting cardiopulmonary disease,[64] gynecological cancers,[65] breast cancer survivors,[58,66,67] and patients from the Pennsylvania Cancer Registry[63]). No study other than the registry-based study[63] was population based: one was a survey of cancer survivors identified from hospital databases and clinic lists at a regional cancer center in Sheffield, United Kingdom;[57] another was a secondary analysis of the LIVESTRONG survey of self-selected respondents from partner organizations and cancer coalitions of the Lance Armstrong Foundation;[64] four were qualitative studies with cancer survivors in Australia,[58] New Zealand,[68] and the United States;[67] and one was a literature review of qualitative and quantitative studies of patient perspectives.[66]

The registry study found that nearly two-thirds of cancer survivors in Pennsylvania had at least one unmet psychosocial need as far out as 3.0 to 4.5 years from diagnosis, and nearly half had over three unmet needs. The greatest need was expressed for emotional needs, followed by physical needs.[63] The LIVESTRONG survey also suggested that physical needs are more likely to be met than either emotional (over 60 percent with unmet needs) or practical needs (over 70 percent with unmet needs).[64] The survey found that "fifty-four percent of respondents indicated they would have liked more followup support after completing treatment" and that "approximately one third left their doctor's office with unanswered questions, and 25 percent reported that the healthcare team did not seem open to discussing their questions or problems."[64, p. 1353-1354] The need for additional information is echoed by the qualitative studies that highlighted the need for more discussion of or information on psychological well-being, postoperative expectations and the reality of functional limitations, and latent physical effects.[58,59,65-67]

KIs offered perspectives on the logistics of offering supportive care services to patients. One KI noted that because the specialist may not have information about counseling services, exercise, and physical therapy, the survivorship clinic is the only mechanism through which

emotional needs, substance abuse, and other diagnoses are discovered. She noted that many supportive care services already exist and that there is "no reason to recreate the wheel and bring it in house." Care providers can just refer patients out as needed. All settings need to be repurposed for survivorship care, but one "does not need to own the resource to use it."

Another KI noted that planning for supportive care resources needs to start during therapy. The KI noted that patients are focused on their health status during treatment. She noted the importance of working with patients from the beginning so that therapy is more compatible with patients' schedules. Patients need to get additional information that will assist them with their work life once their treatment is over. Patients need to know what their rights are, what kinds of accommodations they can get, what information to reveal when looking for a new job, and options for health insurance if they have quit working.

Application of Risk Stratification to Cancer Survivor Programs

The EPC did not find studies describing how risk stratification had been or might be applied to cancer survivorship programs, although studies noted the importance of tailoring SCPs for the individual.[56,59] KIs were in agreement, however, that SCPs need to be tailored for risk. As one KI pointed out, active treatment requires an assessment of risk, so survivorship care should as well. KI s also noted that evidence-based guidelines for survivorship do not account currently for risk stratification and that physicians do not really understand risk and risk of recurrence. So survivorship care models have not incorporated risk, especially related to genetic risks and genetic testing.

Regarding specific sources of risk, KIs noted that comorbidities, particularly for the elderly, may influence the risk of poor outcomes following cancer treatment. Providers may use age as a proxy for comorbidities in risk stratification. Life course also matters: another KI pointed to research showing that a longer chemotherapy course in conjunction with a more cognitively demanding job results in poorer quality of life, worse self-reported health status, and delayed return to work for survivors.

When asked about incorporating patient characteristics into an assessment of risk that might influence the selection of a survivorship care models, one KI offered a three-tiered approach to managing a heterogeneous survivor population. The KI suggested that patients can be characterized as (1) low-risk patients who can be transitioned immediately to a PCP because they do not have much need for long-term oncological care, (2) medium-risk patients who can be transitioned over a 2- to 5-year period to the PCP, and (3) high-risk patients who require ongoing care by both their oncologist and PCPs for life (e.g., transplant patients). Patient advocates also supported the idea of a continuum of need based on patient characteristics and the need for a matching process between patient characteristics and models of care.

Resources Needed to Share Information Among Health Care Providers and With Patients

A mixed-methods project that combined archival data with KI interviews of the leaders of the LIVESTRONG Centers of Excellence identified some frustration with information systems that were designed to support clinical care and billing but were not designed to extract information to develop treatment summaries and SCPs.[46] Communication also emerged as a key issue for both clinicians and patient advocates among our KIs, but their perspectives on resources needed to share information, particularly the role of patient navigators, differed substantially. Clinicians noted their struggles communicating with all members of the team and with patients. Regarding

communicating with other clinicians, one KI noted that having a shared electronic medical record would ease communication among providers and organizations, but the KI was unaware of any resources for provider communication. The KI noted that many hospitals do not have a single electronic health system, and the multiple systems within a hospital often do not communicate. Even when communication occurs (for instance, when an oncology nurse faxes information following a survivorship visit to the PCP's office), it is unclear how well that information is absorbed by the PCP. Survivorship care plans need to be kept cogent, short, and in a format that is likely to be read by all members of the care team, including the PCP. As for communicating with patients, the KI noted that a study of a single survivorship visit found that although patients liked having the visit, they did not retain information presented during the visit, suggesting the need for reinforcement of education provided at the survivorship visit through other methods (e.g., mail, newsletter, additional visits, and telephone followup). Clinicians pointed to patient navigators (either virtual or in person) as a promising avenue to explore in future research.

Patient advocates noted the same concerns as did clinicians with the failure of electronic systems to communicate with one another. Not only are patients failing to receive care coordination in which providers communicate with one another, but they are also subject to treatment decisions from various providers who are working off different sources of information. Patient advocates noted that these gaps in communication place a tremendous burden on already stressed and ill patients to serve as "sole arbiters" of which doctor received which piece of information. Although one patient advocate noted the potential role of an ombudsman to take responsibility for patient coordination, both were cautious about the increasing emphasis on patient navigators. The implementation of patient navigation includes a lot of uncertainties regarding "who does what, how it is funded, [and] how people are held accountable."

Considerations for Evaluating Appropriate Resource Utilization, Cost, Quality of Care, and Outcomes for Survivorship Programs

The EPC did not find studies that listed considerations for evaluating survivorship programs. One KI noted these considerations are much bigger than the field of oncology. At the moment, there is no way to hold anyone accountable for the long-term survivorship of cancer. A larger alignment of incentives, payment reform, and accountable care organizations might make a difference. Regarding specific evaluation considerations, KIs suggested focusing on level of patient satisfaction with their survivorship care, level of education about their disease (including risks and healthy behaviors), and subsequent patient behavior following education.

One KI with a payer perspective noted that coverage for care coordination is possible if care coordination demonstrates (i.e., with evidence) that it can improve patient care or provide clinically meaningful benefit to the patient. He noted that quality of life is a "soft" outcome in coverage determination, so quality of life alone may not be sufficient. Other meaningful measures of the consequences of services include decreased resource utilization rates (e.g., decreased hospitalization, decreased emergency room visits, or even decreases in certain medications that are expensive).

Uptake and Duration of Survivorship Care

The EPC found no studies describing the uptake and duration of survivorship care on the whole. For studies with empirical evidence, the duration of the intervention ranged from 7 weeks[47] to 4.2 years.[69] A structured review of followup of breast cancer patients found some

discrepancies in the literature with guidelines and data suggesting that the frequency and length of the followup service should be tailored to meet the needs of individual patients on the one hand and one study finding evidence of overutilization of followup visits on the other.[60] In addition, we noted that based on a systematic review of 38 articles addressing followup care for breast cancer survivors, neither quality of life nor overall survival was affected by the frequency, duration, or type of followup care received.[60] KIs generally did not comment on or were unaware of generalizable information on the uptake and duration of survivorship care.

Training and Staffing Needed for Survivorship Care

Other than studies described earlier that identified concerns with the level of training or specialized knowledge held by PCPs and nurses, we found no studies suggesting training and staffing needs for survivorship care. KIs were in agreement that no survivor-specific training or certifications exist beyond the underlying certification for each discipline. Although KIs concurred on the need for continuing medical education as a way to train oncologists who are already practicing, they offered different perspectives on how to train the workforce. One KI focused on a teach-the-teacher model as a more promising approach than training an entire workforce on survivorship care through a specialized training track, but another KI noted the importance of better integration of survivorship needs in curricula.

KIs agreed that targeting nurse practitioners in survivorship-related specific training or certification would be particularly helpful and that nurse practitioners were at the right level to address survivorship issues with patients.

GQ 3: Current Evidence on Cancer Survivorship Care

Based on the inclusion criteria described above, we identified nine studies that presented information on models of cancer survivorship care. As discussed in section GQ 1 (above), many taxonomies for survivorship care models are based on the health care provider leading the intervention (e.g., oncologist led, PCP led, nurse led, or shared care), the site of care (e.g., academic center based versus community based), or the main purpose of the model (e.g., transition to primary care). In reviewing these nine identified studies, we identified four model categories based on the main foci of these studies: physician-led models, nurse-led models, models focused on developing SCPs, and a model comparing group versus individual counseling. We discuss these studies in the sections below using these four model categories.

Substantial heterogeneity existed among these studies, including the specific survivorship care models, the type of cancer(s) for which survivors had been treated, and the duration and intensity of followup. Three studies compared differences in survivorship care programs led by physicians.[69-71] All three of these studies involved comparisons between two or more survivorship protocols. Two of the identified studies examined nurse-led survivorship care models.[72,73] Three studies identified in this systematic review of the literature for the Technical Brief focused on developing SCPs.[47,74,75] Although all three involved health care personnel (e.g., all included nurse-led components), the main goal of these models appears to be developing and disseminating a tailored SCP. We have therefore included these models in a separate category. In each of these three models, the SCP was presented to the survivor during a nurse- or nurse practitioner–led visit and was shared with the survivor's PCP. Finally, Naumann et al.[48] examined individual versus group-based counseling and exercise training for cancer survivors.

We present details regarding the design and intervention characteristics of these studies in Tables 2 and 3, respectively. We also present information on dissemination and communications

components of these studies in Table 4. The outcomes for each of these studies are available in Table 5.

Studies of Survivorship Care Models

Design Characteristics

Over half of the included studies (n=5) had a sample size of fewer than 100 patients; the sample sizes ranged from 10 to 968 (Table 2). Six of the studies were comparative in nature, but only three of these six randomized the survivors to a study arm. Other comparative studies involved following cancer survivors who had chosen different types of care programs; these studies correspond more to a "real-world" approach for survivorship care, but this approach increases the likelihood of substantial differences (and resulting bias) among participants in different types of survivorship care. All of the physician-led survivorship model studies were comparative, while fewer of the other studies included comparisons. Similarly, most of the physician-led studies involved randomizing survivors to treatment arms, while few of the other studies included randomization. Two of the nine studies[70,74] included survivors with multiple cancer types: one included survivors with different types of hematological cancers,[70] while the other included survivors of breast, gastrointestinal, lung, and hematologic cancers.[74] All of the studies except the two involving survivors of hematologic malignancies (where stage is not applicable) included survivors who had been diagnosed at multiple stages of disease, although all studies excluded individuals with metastatic disease.

Both the Wattchow[71] and Cannon[70] studies appear to have examined "usual care" for survivors in that there is no specific intervention to modify standard practice patterns. The Kokko[69] study involved what may have been more differences from usual care, in that survivors were randomized to different followup visit intervals and protocols for diagnostic testing (routinely performed versus performed only for clinical reasons).

Intervention Characteristics

The studies' settings primarily comprised cancer centers and hospitals (Table 3). One study was based in a community cancer center.[74] Transition of care was explicitly incorporated as a facet of the survivorship care model only in the three studies focused on SCPs.[47,74,75] Three of the studies, from three different survivorship model categories, included analysis of economic considerations.[69,72,74]

Five of the studies involved survivorship care interventions starting within 1 year following completion of active treatment. The Gates study,[73] by contrast, required that enrollees had completed 5 years following active treatment. Five studies (not the same five with interventions starting within 1 year) included followup of survivors for less than 1 year. In contrast, the Knowles[72] study followed survivors for up to 36 months (for colon cancer survivors) or 48 months (for rectal cancer survivors). Five of the models incorporated telephone contacts as a component of the planned survivorship care.

Information Dissemination and Communications

Four of the studies[47,73-75] involved developing tailored materials for cancer survivors (Table 4). Three of these were the three studies focused on SCPs, which by definition include tailored materials for survivors. All four of these studies also shared these individually tailored materials with the survivor's other health care providers. Although other studies examined may have

shared materials with survivors and their health care providers, this was not explicitly stated. Interestingly, none of the studies involved direct communications or care coordination with the clinicians involved in the survivorship care model and other of the survivor's health care providers.

Outcomes

Quality of life and satisfaction were the most commonly reported outcomes across the studies (Table 5). All but two studies[73,74] included a quality of life outcome; interestingly, both of these studies included developing tailored materials for survivors. The three physician-led models were the only studies to include assessment of resource utilization, although only one of these three[69] explicitly assessed costs. Four studies explicitly included information on disease recurrence, although it is likely that this was tracked in all of the models for the period of survivor followup. Only two studies included assessment of overall survival, which may reflect the short duration of followup for many of the models.

All three of the SCP models examined both distress/anxiety and patient (i.e., survivor) satisfaction. However, in general, studies in the same survivorship care model categories did not assess the same types of outcomes. For example, the two nurse-led interventions did not have any outcomes in common. Depression and well-being were each explicitly assessed in only one study. However, these outcomes may have been incorporated in quality of life assessments included in other studies. Other outcomes present in only a single study included perceptions of health, engagement in health-promoting activities, cancer survivor's knowledge, care coordination/continuity, and unmet needs.

IOM Components Addressed

Table 6 summarizes the IOM survivorship care components addressed by each reviewed model. The model examined by Wattchow addressed two of the four IOM-recommended components of survivorship care: surveillance (for recurrence of colon cancer or development of new cancers) and intervention (to address symptoms potentially associated with cancer or cancer treatment).[71] We were unable to determine which IOM survivorship care components were addressed as part of the Cannon study, although survivors being followed by multiple providers may have had coordination addressed. Similarly, although the Kokko study explicitly addressed the IOM survivorship care component of surveillance, we were unable to determine if any other components were addressed.[69] The model reported by Knowles appears to address only two of the IOM cancer survivorship model components (surveillance and intervention), while the model in the Gates study appears to address all four model components. In particular, the nurse-led program described by Gates explicitly included educating survivors regarding adoption of healthy lifestyle behaviors (prevention component) and sharing the SCP with the survivor's PCP (coordination component), which did not appear to be present in the Knowles model.

The models reported by Curcio and by Jeffords appear to address all four of the IOM survivorship care components.[74] The model examined by Grunfeld appears to address the surveillance, intervention, and coordination components; it is not clear whether it addressed the prevention component.

The group versus individual counseling model addressed the prevention and intervention IOM survivorship care components.

Table 2. Design characteristics of studies of survivorship care models

Type of Survivorship Intervention	Author and Year	Sample Size	Comparison among Survivors (e.g., with usual care, by provider types, single vs. multiple providers, resource utilization frequency)	Survivors Randomized to Study Arm	Survivors with Multiple Cancer Types Included	Survivors across Multiple Stages of Disease Included
Physician-Led Survivorship Care Models	Cannon, 2010[70]	314	X		X	NA
	Kokko, 2005[69]	472	X	X		X
	Wattchow, 2006[71]	203	X	X		X
Nurse-Led Survivorship Care Models	Gates, 2012[73]	60				NA
	Knowles, 2007[72]	60				X
Survivorship Care Models Focused on SCP Development	Curcio, 2011[74]	30			X	X
	Grunfeld, 2011[75]	968	X	X		X
	Jefford, 2011[47]	10				X
Survivorship Care Model Comparing Group vs. Individuals Counseling	Naumann, 2012[48]	40	X			X

Abbreviations: NA = not applicable; vs. = versus.

Note: X indicates study reported the characteristic; blank cells indicate that the study either did not have the characteristic or did not report it.

Table 3. Intervention characteristics of studies of survivorship care models

Type of Survivorship Intervention	Author and Year	Setting	Transition of Care Explicitly Incorporated into Intervention	Economic Considerations Described	Survivorship Intervention Start <1 Year after Completing Treatment	Survivorship Intervention Duration of <1 Year	Model Includes Care Provided by Telephone
Physician-Led Survivorship Care Models	Cannon, 2010[70]	Teaching hospital system				X	
	Kokko, 2005[69]	Hospital department of oncology		X			X
	Wattchow, 2006[71]	Multiple hospitals			X		
Nurse-Led Survivorship Care Models	Gates, 2012[73]	Teaching hospital/ cancer center				X	X
	Knowles, 2007[72]	Hospital surgical department outpatient clinic		X	X		X
Survivorship Care Models Focused on SCP Development	Curcio, 2011[74]	Community cancer center	X	X		X	X
	Grunfeld, 2011[75]	Cancer center and physician office	X		X		
	Jefford, 2011[47]	Teaching hospital	X		X	X	X
Survivorship Care Model Comparing Group vs. Individuals Counseling	Naumann, 2012[48]	NR			X	X	

Abbreviations: NR = not reported; vs. = versus.

Note: X indicates study reported the characteristic; blank cells indicate that the study either did not have the characteristic or did not report it.

Table 4. Information dissemination and communications in survivorship care models studies

Type of Survivorship Intervention	Author and Year	Tailored Materials Prepared for Survivors	Materials Shared with Other Health Care Providers (not directly part of the survivorship care model)	Direct Care Coordination/Communications with Other Health Care Providers (not directly part of the survivorship care model)
Physician-Led Survivorship Care Models	Cannon, 2010[70]			
	Kokko, 2005[69]			
	Wattchow, 2006[71]			
Nurse-Led Survivorship Care Models	Gates, 2012[73]	X	X	
	Knowles, 2007[72]			
Survivorship Care Models Focused on SCP Development	Curcio, 2011[74]	X	X	
	Grunfeld, 2011[75]	X	X	
	Jefford, 2011[47]	X	X	
Survivorship Care Model Comparing Group vs. Individuals Counseling	Naumann, 2012[48]			

Abbreviations: vs. = versus.

Note: X indicates study reported the characteristic; blank cells indicate that the study either did not have the characteristic or did not report it.

Table 5: Outcomes of cancer survivorship models studied

Type of Survivorship Intervention	Author and Year	Quality of Life	Depression	Anxiety/ Distress	Well-being	Satisfaction	Resource Utilization	Adherence to Planned Followup	Disease-free Period	Overall Survival	Recurrence	Perceptions of health	Engagement in Health-Promoting Activities	Cancer Survivors' Knowledge	Coordination/ Continuity of Care	Unmet Needs
Physician-Led Survivorship Care Models	Cannon, 2010[70]	X				X	X									
	Kokko, 2005[69]	X					X		X	X	X					
	Wattchow, 2006[71]	X	X	X		X	X			X	X					
Nurse-Led Survivorship Care Models	Gates, 2012[73]											X	X			
	Knowles, 2007[72]	X				X		X			X					
Survivorship Care Models Focused on SCP Development	Curcio, 2011[74]			X		X		X						X		
	Grunfeld, 2011[75]	X		X		X					X				X	
	Jefford, 2011[47]	X		X		X										X
Survivorship Care Model Comparing Group vs. Individuals Counseling	Naumann, 2012[48]	X			X											

Abbreviations: vs. = versus.

Note: X indicates study reported the characteristic; blank cells indicate that the study either did not have the characteristic or did not report it.

Table 6. IOM survivorship care components

Type of Model	Author and Year	Prevention	Surveillance	Intervention	Coordination
Physician-Led Survivorship Care Models	Cannon, 2010[70]				
	Kokko, 2005[69]		X		
	Wattchow, 2006[71]		X	X	
Nurse-Led Survivorship Care Models	Gates, 2012[73]	X	X	X	X
	Knowles, 2007[72]		X	X	
Survivorship Care Models Focused on SCP Development	Curcio, 2012[74]	X	X	X	X
	Grunfeld, 2011[75]		X	X	X
	Jefford, 2011[47]	X	X	X	X
Survivorship Care Model Comparing Group vs. Individual Counseling	Naumann, 2012[48]	X		X	

Abbreviations: vs. = versus.

Note: X indicates study reported the characteristic; blank cells indicate that the study either did not have the characteristic or did not report it.

Conclusions From the Literature Review

Our review of the studies identified by this systematic review of the literature for the Technical Brief indicates a number of important findings regarding the model-of-care literature.

First, we reviewed a large body of literature, but we were only able to identify nine published studies that met our definition of survivorship models (i.e., programs for cancer survivors that addressed two or more different health care needs). Much of the available literature described only a single service for cancer survivors and thus did not correspond to a holistic and coordinated model or meet our inclusion criteria.

As discussed above, the nine identified studies are heterogeneous with respect to the type of survivorship care model, characteristics of the survivors participating, and intensity and duration of the interventions. For example, time since completion of active treatment varied from essentially immediately following completion (Kokko et al.[69]) to a median of 12 years (Gates et al.[73]). This heterogeneity provides challenges in identifying trends or making comparisons across the different models. At this point, the described models serve as "stand-alone" examples, with only limited ability to assess comparative effectiveness or draw generalizable conclusions for the overall survivor population.

Outcomes assessed across the identified studies were also heterogeneous. Many of the studies assessed health-related quality of life, but differing instruments were used. Some studies assessed knowledge, satisfaction, adherence to recommended followup, or resource utilization, but this was also variable. The lack of a standard or minimal set of metrics to evaluate the impacts of survivorship care models creates substantial barriers to making comparisons among alternative models. The models varied in terms of the IOM survivorship care components addressed. Most models addressed surveillance (for recurrent or new cancers) and intervention (for symptoms or conditions resulting from the cancer or cancer treatment). Fewer models addressed prevention (i.e., encouragement to adopt healthy lifestyle behaviors) or care coordination. Further, studies that did incorporate care coordination largely involved only sharing information (such as an SCP) with the survivor's PCP. Models may need to explore more detailed approaches to care coordination, including the resources needed to exchange information among diverse groups of health care providers, survivors, and caregivers.

In general, nurse-led models and models focused on developing SCPs appeared to address more IOM components. Overall, it is not surprising that the models identified for this study did not address all IOM components. As reported by Salz et al.,[76] only 43% of National Cancer Institute-designated cancer centers present SCPs to their breast or colorectal cancer survivors, and none of these address all components recommended by the IOM.

Within each study, participant characteristics were also heterogeneous; for example, several studies involved individuals diagnosed with stage I through stage III disease. None of the studies described specific risk stratification protocols, where survivors who had more extensive disease at diagnosis and/or who received more intensive therapy were provided with different types of information or different supports than were those with less extensive disease or treatment. Several of the review models included individualized components (e.g., SCPs), which may have been tailored to reflect individual risk levels, but this was not explicitly stated. Completeness of information reporting in these nine studies also varied and, for certain types of study data, information was largely absent. For example, none of the studies reported any adverse events or unintended consequences of the survivorship care model, such as overuse of services or duplicate testing. It may be that no such unintended consequences occur; however, it would be useful for researchers to explore this issue and comment on such negative results if that is the case. This

may also be useful as an outcome measure for survivorship care reflecting effectiveness of communication and coordination of care.

Other than the report by Curcio et al.,[74] the reviewed studies either included few nonwhite survivors or did not report the proportion of nonwhite survivors participating. Although some studies took place in countries with low proportions of nonwhite individuals (e.g., Finland), the low level of involvement of nonwhite survivors parallels low participation rates observed in therapeutic cancer clinical trials. African-American and Hispanic individuals are significantly less likely to participate in cancer clinical trials than white individuals.[77] Patient-level barriers, such as sociocultural factors and distrust of the medical establishment; trial design factors such as eligibility criteria; and provider-level factors have been reported to limit participation by African Americans in therapeutic cancer clinical trials.[78] It will be important for developers of cancer survivorship care models to consider potential barriers to participation by racial/ethnic minorities and other underserved populations and to provide information on enrollment by these disparate groups.

Several of the identified studies do not include a "usual care" arm. To evaluate the effectiveness of a survivorship care model and compare effectiveness among differing models, a common "baseline" of standard survivorship care is needed. The absence of comparisons with standard survivorship care practices (i.e., in the absence of a protocol-specified intervention) limits the ability to assess whether a more integrated or comprehensive model of survivorship care would differ from a less integrated/comprehensive model in clinical outcomes or efficiency of care delivery for cancer survivors. Similarly, the absence of comparison to usual care prevents assessment of the potential harms that may result from survivorship care models. Additional research is needed to explore whether (and how) various models of survivorship care are likely to improve outcomes for cancer survivors compared with current survivorship care practices.

Findings From KIs

Several KIs provided information on survivorship care models. One KI commented that survivorship clinics at academic institutions, which provide medical care as well as address psychosocial needs, are the only model she is aware of.

Another KI described a survivorship care model that has been funded by the LIVESTRONG Foundation and the National Cancer Institute's Community Cancer Center Program. The initial survivorship visit is held on the same day as the first followup oncologist meeting. This survivorship visit is led by an advanced practice nurse and lasts 90 to 120 minutes. Components of the survivorship visit include developing a breast cancer treatment summary and care plan (for breast cancer survivors), assessing the survivor's immediate health needs and signs of recurrence and late effects of treatments, offering assistance with coordinating the patient's care among existing providers, and providing appropriate referrals. The KI and his colleagues have assessed changes in quality of life, satisfaction, and cancer concerns from baseline to 6 months for participants in this program.

Another KI described three survivorship care programs at her institution:

(i) *Cancer "transition" health care delivery program*. This program is focused on breast cancer survivors but is expanding to other survivor populations. It involves a series of group medical visits with cancer survivor themes led by PCPs in partnership with oncologists. The program provides multidisciplinary, coordinated care delivery with an emphasis on cancer prevention and screenings. Survivors also complete an SCP.

(ii) *One-time consultation with multiple providers.* This approach assesses current needs and includes a care plan for preventative health care needs and surveillance. This consultation was a very resource-intensive model because it was not offered in conjunction with a patient's oncology visit. Plans are to have more of the screening and assessment of survivorship needs done in the disease site clinic; based on that screening and assessment, survivors will receive referrals to other providers to address those needs.

(iii) *Adult survivors of childhood cancers program*. This program involves one or two consultations with multiple health care providers. The survivors and PCPs receive a care summary that includes general health care prevention and surveillance strategies.

GQ 4: Gaps in Knowledge and Future Research Needs for Models of Adult Cancer Survivorship Care

The literature includes information on a number of different types of survivorship care programs.[44] Methods for developing and implementing survivorship care programs vary and depend on organizational, leadership support and the presence of an internal champion.[46] Different settings include academic models, community practice models, and shared care.[42] As noted in the discussion for GQ 3, little data exist on how many of these models have been implemented, evaluated, or compared with standard care. Few studies have evaluated the structural or process barriers or constraints to offering survivorship care, such as incentives and disincentives to continue surveillance of recurrence and resolution of side effects; reimbursement for survivorship care; survivor's perspective on following up with their oncologist, with whom they may have become emotionally attached; and oncologists' perspectives on continued care provision for survivors who are doing well, which may provide emotional and economic benefits for oncologists. As survivorship care evolves, it will be important to include evaluation of the infrastructure needed for delivering optimal care as well as relevant outcomes.[79,80] As we learn more about the needs and problems of long-term survivors, a "one-size-fits-all" model for survivorship care will likely not be as relevant as a triaged or tailored approach.

Gaps in Knowledge

The review of the literature and interviews with KIs indicated gaps in knowledge that need to be addressed to help guide future cancer survivorship model development. First, studies need to adequately describe the model(s) being examined and provide more detailed information to assist in comparing results of one study with those of other studies and assessing the generalizability of any one model. When possible, studies of survivorship care models should compare their structures, processes, and outcomes with data from the "standard of care" (which, as discussed in the "Next Steps" section below, is not well defined) or from other survivorship models.

Second, studies of survivorship care, whether presented as models or not, need to provide additional data on the long-term or late effects of treatments received by adult cancer patients. This may support better risk stratification of survivors within models based on projected recurrence and late effects and facilitate different types or levels of survivorship care based on individual risk profiles. For example, the needs of patients with low risk of recurrence or treatment effects (e.g., early-stage colon cancer) might be best served with a transition to a primary care model, while patients at high risk for problems (e.g., bone marrow transplant survivors) might be better served in a disease-specific or multidisciplinary clinic. However, such risk-stratification in survivorship care will be difficult to do without longitudinal data on

survivors over long periods of time. Further, heterogeneity in the definition of survivors will also add challenges to this goal. It may be most practical to define a survivor as a person who has completed active acute cancer treatment and is on observation or maintenance therapy when studying models of survivorship care.

Third, KIs identified a gap in understanding survivors' needs, especially in racial/ethnic minority populations.

Finally, an improved understanding of barriers to survivorship care is necessary. Regardless of the model adopted, barriers identified by KIs include financial incentives/disincentives, clinical information systems to identify candidates for survivorship care and to provide information, lack of organization support, and lack of health care provider training about survivorship issues.

Future Research Needs

Research is lacking on models of survivorship care or its components. As a result, a number of areas need to be explored, such as fostering organizational changes to deliver survivorship care, determining the frequency and length of care for survivors,[46] measuring patient morbidity associated with followup appointments,[60] developing evidence-based followup guidelines, and bridging the gap between oncologists and PCPs in delivering long-term followup care.[44]

Different models of care and components of care need to be evaluated, particularly on measures of over or underuse of health care.[46] Evidence-based surveillance plans currently only exist for breast and colorectal cancers and need to be expanded to other cancers.

Long-term patient-reported outcomes should be collected to better predict higher and lower risk groups. Understanding what contributes to organizational culture change to clinically support survivorship care is needed.

KIs raised other questions raised include the following:

- What are the needs of survivors over time?
- How do we optimize wellness in survivors? What is the role of self-management programs?
- What models of care have better outcomes?
- Should survivorship care be imbedded in cancer care or provided as a separate service?
- Do we need an oncology medical home?
- Could a virtual patient navigator program facilitate transitions along the cancer continuum?

Summary and Implications

An overarching theme across the literature and key informant (KI) interviews relates to the heterogeneity of existing research and practice. Our systematic review of the evaluations of existing programs for the Technical Brief classified interventions into four categories: nurse led, physician led, survivorship care plan centered, and individual or group counseling models. Within each category, we found substantial variation in the types of cancers; timing, components, intensity, and followup of care delivery; and types of outcomes evaluated. Although this report only includes studies of individuals who had completed active treatment, there is also heterogeneity in how the field defines a "cancer survivor."

Another finding is the paucity of evidence regarding fundamental questions such as what is a model and will a model of cancer survivorship care result in improved outcomes for patients when compared with usual care (and what constitutes "usual care" for a cancer survivor). As

noted in the methods section, we focused on studies that addressed multiple needs of survivors. If we had elected to broaden our focus to studies addressing single needs of survivors, our yield would have been larger, but these studies would not have spoken to the issue of models of care.

A related question is whether programs addressing only two different needs for cancer survivors are sufficiently comprehensive to be considered models. We had discussed defining survivorship care models as programs that addressed all four of the components listed by the IoM, but we identified few studies of survivorship care models even using this expanded (two needs) definition.

Our findings suggest that models of survivorship care are highly idiosyncratic, or individualized to the institution or organization where they are based; the care provided in these models may depend on the relationship between the provider and the survivor, the survivor's risks associated with the disease, and the practice setting(s) where survivorship care occurs. Thus, it may be difficult to pull out commonalities among different models. In addition, current reimbursement rules may disincentivize new care models, so oncologists continue to see cancer survivors. However, an anticipated workforce shortage of oncologists may require new approaches such as the expanded use of nurse practitioners and physician assistants, shared care with primary care providers, and patient navigators. Concerns about these alternatives include payment considerations, adequacy of training, and greater fragmentation of care.

Next Steps

Based on the literature review and interviews with key informants (KIs), we identified a number of questions that need to be explored for optimal development of cancer survivor care models. For each question, we provide suggestions for the cancer survivorship community, including survivors, clinicians, policymakers, and researchers, to address these questions.

1. What is a "model of cancer survivorship care"? How should models of care be defined or specified to differentiate them from other types of survivorship care services?

   Suggestions for addressing this question: Stakeholders in the cancer survivorship community need to agree on a common definition for "survivorship models" and on a taxonomy for types of models. A meeting with broad participation may be useful for reaching consensus (or at least general agreement) on this topic.

2. In evaluating the outcomes associated with survivorship care models, what should constitute "usual care"? KIs interviewed for this report generally agreed that currently no standard survivorship care program exists.

   Suggestions for addressing this question: Studies are needed to better understand the current experiences of cancer survivors, particularly those who do not receive followup care at academic centers. This will likely include analyses of existing data sets (e.g., claims data or electronic medical records) as well as focus groups or interviews with survivors, clinicians, and other stakeholders.

3. What is the most opportune time following completion of active treatment to initiate a survivorship care program? Does this vary based on the type of cancer, stage of cancer at diagnosis, and/or other patient sociodemographic and clinical characteristics?

4. What is the optimal period for repeated visits or other contacts with cancer survivors? Does this depend on patient sociodemographic or clinical characteristics? Are repeated

"face-to-face" survivorship visits needed or does a one-time visit provide comparable outcomes?

5. What is the optimal followup period for a survivorship care model? What is the minimum period needed to assess the potential impacts of a model? What period is needed to capture a majority of the developments of late effects, recurrences, or new cancers among survivors?

   Suggestions for addressing this question: Input from cancer survivors is needed regarding changes in their support needs at different periods following completion of active treatment. Clinicians and researchers developing or implementing survivorship care programs and models need to consider this input and align programs with the needs of survivors from differing periods. Evaluations of survivorship care models should examine difference in outcomes based on time since completion of active treatment and should provide clear information on the time since treatment completion among participation and stratification of outcomes by time since completion.

   Survivorship care programs need to provide repeated assessments over time of their key outcomes to explore how (or whether) outcomes change with additional followup interactions and/or increased duration of followup. Similarly, programs need to consider survivors who discontinue participation in programs, including whether participation for an initial period results in longer-term benefits and why survivors choose to discontinue participation. Once a reasonable body of information is available on how survivors' needs and program effectiveness vary by time since completion of active treatment and optimal periods for survivorship contacts and followup of care, recommendations can be developed to guide future models.

6. What is the minimum set of outcomes that should be examined in all studies of survivorship care models and how should they be measured? At present, diverse and largely incompatible outcomes are assessed, presenting barriers to comparisons across differing models.

   Suggestions for addressing this question: As with Question 1, answering this question likely requires discussions among a broad group of stakeholders in the cancer survivorship community to agree on a minimal set of outcome measures to be assessed by all survivorship care models. Clearly, models may wish to assess additional outcomes that are specific to the survivor population being targeted or the services being offered by a model. However, all models should provide at least an agreed-upon set of common outcome measures. Journals, conferences, and grant-funding organizations could require this information from survivorship care programs and not accept those that are lacking the minimal set of outcomes.

7. For models involving SCPs, what are the key elements to include? How can programs balance the need to be comprehensive in the information provided versus "overloading" survivors with too much information that might all be ignored?

   Suggestions for addressing this question: A substantial body of literature exists regarding SCPs. Compiling a compendium of this literature and identifying and comparing the specific elements included in each SCP would provide a useful resource. Input from survivors as to the components of SCPs that were (or were not) useful will

also be key. Certain elements will be required for all SCPs, such as details of the diagnosis and treatments received and recommended surveillance. However, future programs or models involving SCPs may want to explore including different subsets of SCP elements in two or more participant groups to assess the impacts of these elements on outcomes among survivors and their clinicians.

8. How do survivorship care models differ with respect to resource utilization, cost, cost-effectiveness, and efficiency? Are some models more advantageous in settings with limited resources or finances?

   Suggestions for addressing this question: As discussed repeatedly in this report, cancer survivorship models display tremendous heterogeneity. Therefore, at the present time, comparisons of resource utilization, cost, cost-effectiveness, and efficiency among survivorship models are not feasible; the resource utilization and costs from a model are likely not generalizable across survivor populations, settings, and model types. As survivor models adopt more common practices and outcome measures, comparisons of resource utilization and costs may become practical.

9. How do models need to be tailored to optimally benefit survivors from underserved populations, including those from racial/ethnic minorities, low socioeconomic status, older age groups, and low health literacy?

   Suggestions for addressing this question: Most of the models examined for this report either included low numbers of survivors from underserved populations or did not report the proportion of underserved individuals participating. Survivorship care models should focus more strongly on recruitment and outreach to attract survivor populations that reflect the overall population of adults treated for cancer. In addition, the models we examined were largely based at academic centers or hospitals with substantial research experience. Models based in settings that focus on survivor care for underserved populations, such as Federally Qualified Health Centers, are needed to collect information from and develop approaches tailored for these vulnerable groups.

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60. Collins RF, Bekker HL, Dodwell DJ. Follow-up care of patients treated for breast cancer: a structured review. Cancer Treat Rev. 2004 Feb;30(1):19-35. PMID: 14766124.

61. Hill-Kayser CE, Vachani C, Hampshire MK, et al. High level use and satisfaction with internet-based breast cancer survivorship care plans. Breast J. 2012 Jan-Feb;18(1):97-9. PMID: 22098063.

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Appendix A. Key Informant Interview Methodology

We adhered to the Office of Management and Budget (OMB) requirements and limited standardized questions (the list of GQs) to no more than nine nongovernment-associated individuals. As a result, we did not need to obtain OMB clearance for the interviews.

After review and approval of the completed Disclosure of Interest forms for the proposed KIs by the Agency for Healthcare and Quality (AHRQ), over a 3-week period, we conducted interviews with 10 selected KIs of which two were government-associated individuals and did not count toward the OMB limit of nine individuals who could be interviewed without clearance. The interviews were a combination of individual key informants (KIs) and groups of KIs based on availability and concordance of perspectives. A co-investigator from the EPC team led each of the KI interviews, and the Task Order Officer (TOO) was in attendance for all of the interviews along with other EPC team members. The recorded KI interviews ranged in duration from 0.5 hours to 1.5 hours. Following each interview, the Evidence-based Practice Center (EPC) summarized the interviews in writing by incorporating summary notes prepared by team members; interview recordings; and, for some, a professional transcription of the interview. We then submitted notes to the TOO for documentation. Using NVivo® qualitative software (v9.0), the EPC coded the KIs' responses by relevant Guiding Questions (GQs) and subquestions and generated summary reports by subquestion for analysis by the authors. Authors evaluated summary reports, corrected or added codes by referring to the original summary notes, and identified key themes from multiple perspectives. In addition, authors also identified unique perspectives from KIs.

We modified the order of the GQs to better align the topical content under the GQ domain. For instance, in KI interviews conducted for this project (described below), rather than initiating the interview with a question about models of care that have been widely used, we asked KIs to first describe usual care for survivors and then describe models of care. We also rephrased some of the questions to better clarify the intent of the question to facilitate KI discussions. As an example, we combined two questions focusing on gaps in knowledge holding back the diffusion of survivorship care and new research necessary to reduce uncertainty in decision, by asking, "Are gaps in knowledge holding back the diffusion of survivorship care? What are the most important knowledge gaps to fill through new research to reduce uncertainty in decision?"

1. **Guiding Question 1: Overview of cancer survivorship care**
    1. Is it possible to generalize "usual care" for cancer survivors in the United States? If so, how would you describe the nature of usual care for survivors of cancer? If not, can you describe some of the most common care practices?
    2. How would you define a "model" of survivorship care as opposed to separate health care services that may be offered to cancer survivors? Are there specific components of care that need to be present for services to be considered a model?
    3. What are the different models of cancer survivorship care that have been most widely used? *[For all KIs except for Research: What is your current or past experience with using different models of care?]*
    4. What are the advantages and disadvantages of these models, compared with one another and with usual care?
    5. How widely is survivorship care offered? For how long?
    6. Are there any potential safety issues and harms resulting from care provided in the models? If so, what are they?

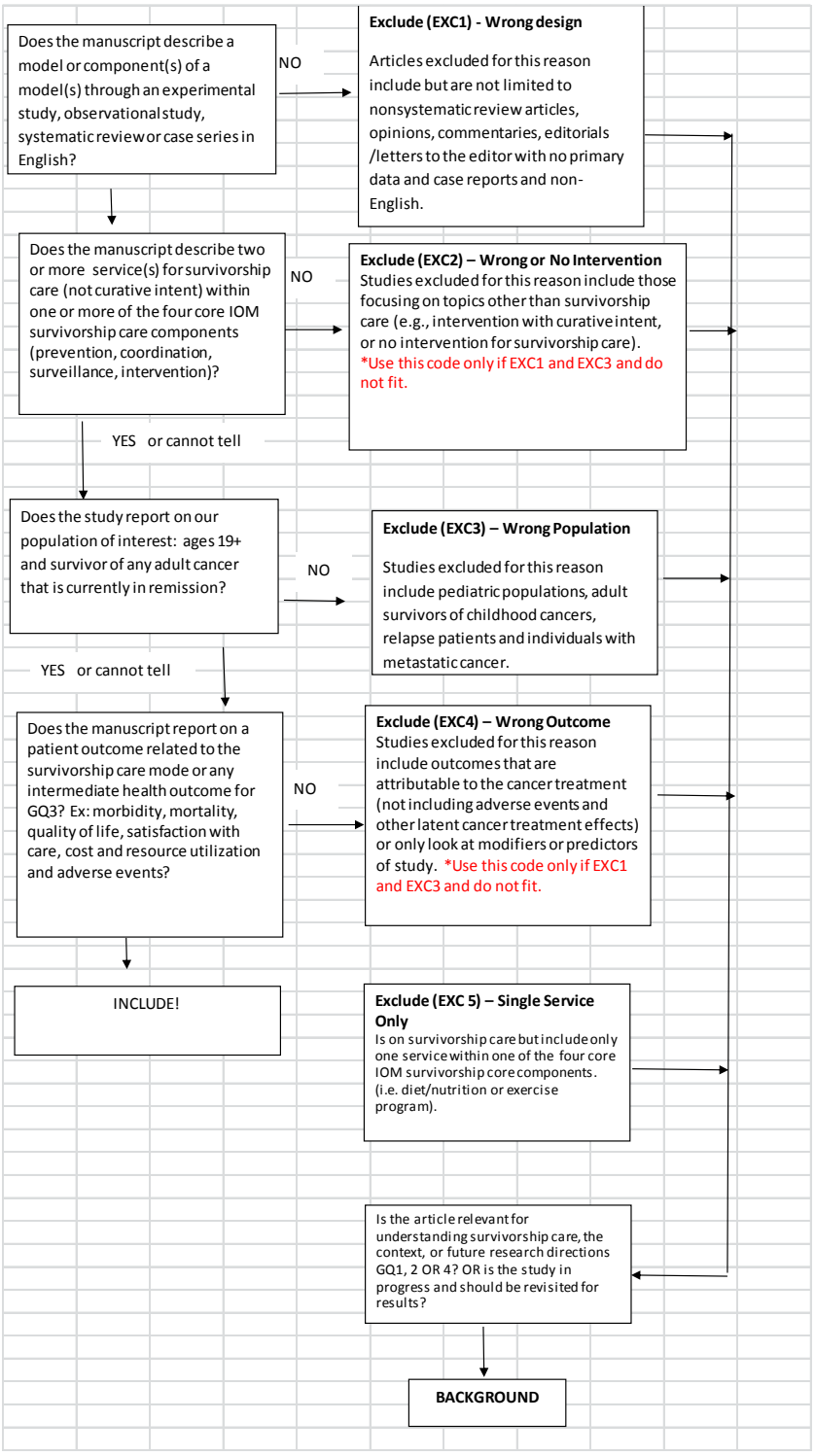
2. **Guiding Question 2: Context in which cancer survivorship care is used**
    1. Do patients and clinical care providers choose among survivorship care programs? If so, how do they decide among programs? If not, why not—are clinicians generally aware of (or affiliated with) only a single program, or are patients generally informed of more than one option for survivorship care?
    2. How do models of care vary based on
        a. setting,
        b. organizational structure,
        c. provider type (including in the context of transitions of care),
        d. payment considerations, and
        e. patient characteristics such as age, race, cancer type, stage of disease, other risk stratification issues?
    3. What associated supportive care resources are commonly incorporated in survivorship care programs? What supportive care resources that are not present are needed? *(PROBE: Supportive care for caregivers/family of patient, or social support as a supportive care resource? Or both?)*
    4. How is (or could) risk stratification (be) applied to cancer survivor programs? *[For patient advocates only: If patients who are considered at higher risk for problems, that is, latent effects, are there programs or resources that can address those specific needs?)*
    5. What kinds of resources (e.g., health information technology) are available or needed to share information among health care providers and with cancer survivors?
    6. What are important considerations for evaluating appropriate resource utilization, cost, quality of care, and outcomes for survivorship programs? *[When you are considering your quality of care or minimizing costs what factors are important to weigh?]*
    7. What kinds of training and certification are required for clinicians involved in survivorship programs? What modifications to current training, certification, and staffing are in development?

3. **Guiding Question 3: Current evidence**
    1. Do you have any information that may be useful to us in our evaluation of the current evidence?

4. **Guiding Question 4: Gaps in knowledge and future research needs**
    - Are gaps in knowledge holding back the diffusion of survivorship care? *[could suggest other gaps such as reimbursement or other factors, if prompted by interviewee]*
    - What are the most important knowledge gaps to fill through new research to reduce uncertainty in decision?
    - Are there models of survivorship care that are planned but not yet implemented?
    - What are the differences between existing models of survivorship care and new and emerging models of survivorship care?
    - What are possible areas of future research?

Appendix B. Sample Data Abstraction Forms

Title and Abstract Review Form



Full Text Review Form

Reviewer	RefID	First Author Last Name	Study Year	Title	Relevant for GQ3: Is a Model of care or are components of model described? Is there evidence presented on the patients receiving the components of care?	Only for GQ3 Specific services for survivorship described in article	Only for GQ3 IOM survivorship care component	Relevant for GQ1: Overview of Cancer Survivorship Care?	Relevant for GQ2: Context in which cancer survivorship care is used?	Relevant GQ4: Gaps in Knowledge and Future Research Needs?	General Background (not specific to any GQ or "in progress" study)	For All GQs Study Design (Specify "Other" in comments)	Comments

Abstraction Form

Identifiers			
RefID	**First author's last name**	**Year**	**Trial name** *If present/applicable*

Population characteristics						
Type of cancer	**Stage of disease at diagnosis**	**Treatment history**	**Time since active treatment**	**Baseline age mean (range)**	**Baseline % female**	**Baseline % non-white**
Type of cancer: N (%)	Stage of disease at diagnosis: N (%)	As described	Preferably mean days/weeks/ months (SD)	Overall and by group G1 is always the intervention group; the control group is always the last to be listed)		Only report % non-white when possible; only give further breakdown if not possible to determine % non-white
				Overall: G1: G2:	Overall: G1: G2:	Overall: G1: G2:

Outcomes measured		
Intermediate, health, patient-centered outcomes	**Adverse events**	**Cost and resource utilization**
List all intermediate, health, and patient-centered outcomes measured. Describe the length of followup after the intervention ends, e.g., HbA1c (3 months)	List all unintended consequences measured. Describe the length of followup.	List all costs, ER visits, doctor visits, hospitalizations measured. Describe the length of followup.

Comments

Appendix C. List of Excluded Studies

(EXC1)—Wrong design

1. Collins RF, Bekker HL, Dodwell DJ. Follow-up care of patients treated for breast cancer: a structured review. Cancer Treat Rev. 2004 Feb;30(1):19-35. PMID: 14766124.
2. Howard-Ruben J. Nurses help patients thrive and survive from diagnosis to treatment and beyond. ONS News. 2005 Jun;20(6):1, 4-6. PMID: 15997995.
3. Jacobsen PB. Clinical practice guidelines for the psychosocial care of cancer survivors: current status and future prospects. Cancer. 2009 Sep 15;115(18 Suppl):4419-29. PMID: 19731353.
4. Jersild S. Programs work toward transitioning survivors to primary care. Oncology (Williston Park). 2007 Apr;21(4 Suppl):40-3. PMID: 17508501.
5. Katz A. Breast cancer and women's sexuality. Am J Nurs. 2011 Apr;111(4):63-7. PMID: 21451301.
6. Mitka M. Young adult cancer survivors face barriers to receiving primary care. JAMA. 2012 Oct 24;308(16):1618-9. PMID: 23093148.
7. Smith S, Landier W, Francisco L, et al. Development of a customizable, health promotion-oriented prostate cancer survivorship care plan. Oncol Nurs Forum. 2009;36(3):19-20. PMID: 43539818.
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9. Goroncy N, Wheeler G, Dwyer M, et al. Sharing the care: an innovative health program for childhood and adult cancer survivors between the late effects clinic at Peter Maccallum Cancer Centre and their GP's. Pediatr Blood Cancer. 2011;57(5):826.
10. Juth V, Cohen Silver R, Sender L, et al. Stressors of pediatric cancer care: the influence of interpersonal interactions. Clin Transl Sci. 2011;4(2):131.
11. Rogers P, Barr RD, Schacter B. The Canadian task force on adolescents and young adults (AYA) with cancer; A process for change. Pediatr Blood Cancer. 2011;57(5):839.
12. Sullivan M, Yallop K, Simpson R, et al. Leap-it-a passport to health; an integrated late effects assessment programme and electronic health passport for long term followup of child cancer survivors in New Zealand. Pediatr Blood Cancer. 2011;57(5):710.

(EXC2)—Wrong or No Intervention

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2. Barg FK, Cronholm PF, Straton JB, et al. Unmet psychosocial needs of Pennsylvanians with cancer: 1986-2005. Cancer. 2007 Aug 1;110(3):631-9. PMID: 17592828.
3. Becker H, Rechis R, Kang SJ, et al. The post-treatment experience of cancer survivors with pre-existing cardiopulmonary disease. Support Care Cancer. 2011 Sep;19(9):1351-5. PMID: 20658347.
4. Belkora J, Katapodi M, Moore D, et al. Evaluation of a visit preparation intervention implemented in two rural, underserved counties of Northern California. Patient Educ Couns. 2006 Dec;64(1-3):350-9. PMID: 16904859.
5. Binkley JM, Harris SR, Levangie PK, et al. Patient perspectives on breast cancer treatment side effects and the prospective surveillance model for physical rehabilitation for women with breast cancer. Cancer. 2012 Apr 15;118(8 Suppl):2207-16. PMID: 22488695.

6. Bishop MM, Lee SJ, Beaumont JL, et al. The preventive health behaviors of long-term survivors of cancer and hematopoietic stem cell transplantation compared with matched controls. Biol Blood Marrow Transplant. 2010 Feb;16(2):207-14. PMID: 19781657.

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8. Cappiello M, Cunningham RS, Knobf MT, et al. Breast cancer survivors: information and support after treatment. Clin Nurs Res. 2007 Nov;16(4):278-93; discussion 94-301. PMID: 17991908.

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10. Clauser SB, Arora NK, Bellizzi KM, et al. Disparities in HRQOL of cancer survivors and non-cancer managed care enrollees. Health Care Financ Rev. 2008 Summer;29(4):23-40. PMID: 18773612.

11. Hill-Kayser CE, Vachani C, Hampshire MK, et al. High level use and satisfaction with internet-based breast cancer survivorship care plans. Breast J. 2012 Jan-Feb;18(1):97-9. PMID: 22098063.

12. Husson O, Holterhues C, Mols F, et al. Melanoma survivors are dissatisfied with perceived information about their diagnosis, treatment and follow-up care. Br J Dermatol. 2010 Oct;163(4):879-81. PMID: 20854404.

13. Jones JM, Ferguson S, Edwards E, et al. Experiences of care delivery: endometrial cancer survivors at end of treatment. Gynecol Oncol. 2012 Mar;124(3):458-64. PMID: 22079362.

14. Keating NL, Landrum MB, Guadagnoli E, et al. Surveillance testing among survivors of early-stage breast cancer. J Clin Oncol. 2007 Mar 20;25(9):1074-81. PMID: 17369571.

15. Khan NF, Ward A, Watson E, et al. Long-term survivors of adult cancers and uptake of primary health services: a systematic review. Eur J Cancer. 2008 Jan;44(2):195-204. PMID: 18035534.

16. Lauver DR, Connolly-Nelson K, Vang P. Stressors and coping strategies among female cancer survivors after treatments. Cancer Nurs. 2007 Mar-Apr;30(2):101-11. PMID: 17413775.

17. Lavoie Smith EM, Skalla K, Li Z, et al. Assessing cancer survivors' needs using web-based technology: a pilot study. Comput Inform Nurs. 2012 Feb;30(2):71-81. PMID: 22258317.

18. Mandelblatt JS, Lawrence WF, Cullen J, et al. Patterns of care in early-stage breast cancer survivors in the first year after cessation of active treatment. J Clin Oncol. 2006 Jan 1;24(1):77-84. PMID: 16382116.

19. Marbach TJ, Griffie J. Patient preferences concerning treatment plans, survivorship care plans, education, and support services. Oncol Nurs Forum. 2011 May;38(3):335-42. PMID: 21531683.

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23. Tan AS, Moldovan-Johnson M, Parvanta S, et al. Patient-clinician information engagement improves adherence to colorectal cancer surveillance after curative treatment: results from a longitudinal study. Oncologist. 2012;17(9):1155-62. PMID: 22858794.

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(EXC3)—Wrong Population

1. Bains M, Munir F, Yarker J, et al. Return-to-work guidance and support for colorectal cancer patients: a feasibility study. Cancer Nurs. 2011 Nov-Dec;34(6):E1-12. PMID: 21372705.

2. Bosompra K, Ashikaga T, O'Brien PJ, et al. Knowledge about preventing and managing lymphedema: a survey of recently diagnosed and treated breast cancer patients. Patient Educ Couns. 2002 Jun;47(2):155-63. PMID: 12191539.

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4. Choi KH, Park JH, Park SM. Cancer patients' informational needs on health promotion and related factors: a multi-institutional, cross-sectional study in Korea. Support Care Cancer. 2011 Oct;19(10):1495-504. PMID: 20694821.

5. Chung MH, Chao TY, Chou KR, et al. Health-promoting lifestyle factors of cancer survivors in Taiwan. Cancer Nurs. 2009 May-Jun;32(3):E8-E14. PMID: 19295426.

6. Cotterell P, Harlow G, Morris C, et al. Service user involvement in cancer care: the impact on service users. Health Expect. 2011 Jun;14(2):159-69. PMID: 21029279.

7. Sweeney L, Halpert A, Waranoff J. Patient-centered management of complex patients can reduce costs without shortening life. Am J Manag Care. 2007 Feb;13(2):84-92. PMID: 17286528.

8. Tamminga SJ, de Boer AG, Bos MM, et al. A hospital-based work support intervention to enhance the return to work of cancer patients: a process evaluation. J Occup Rehabil. 2012 Dec;22(4):565-78. PMID: 22699884.

9. Yi M, Park EY. Effects of breast health education conducted by trained breast cancer survivors. J Adv Nurs. 2012 May;68(5):1100-10. PMID: 21880060.

10. van de Poll-Franse LV, Nicolaije KAH, Vos MC, et al. The impact of a cancer Survivorship Care Plan on gynecological cancer patient and health care provider reported outcomes (ROGY Care): study protocol for a pragmatic cluster randomized controlled trial. Trials. 2011;12(1):256-63. PMID: 72417776.

11. Annunziata MA, Giovannini L, Muzzatti B, et al. Sexuality and intimacy in long-term cancer survivors: Explorative results from the first Italian cancer survivor clinic. Psychooncology. 2011;20:271.

12. Konopacki J, Porcher R, Robin M, et al. Long-term follow-up of allogeneic hematopoietic stem cell transplantation in patients with severe alpastic anemia after cyclophosphamide plus antithymocyte globulin conditioning regimen. Blood. 2011;118(21).

13. Trevino K, Fasciano K, Block S, et al. Young adults with advanced cancer: the relationship between social support and psychological well-being. Psychooncology. 2012;21:6-7.

14. Nieuwenhuijsen K, Bos-Ransdorp B, Uitterhoeve LL, et al. Enhanced provider communication and patient education regarding return to work in cancer survivors following curative treatment: a pilot study. J Occup Rehabil. 2006 Dec;16(4):647-57. PMID: 17063404.

15. Rao AV, Hsieh F, Feussner JR, et al. Geriatric evaluation and management units in the care of the frail elderly cancer patient. J Gerontol A Biol Sci Med Sci. 2005 Jun;60(6):798-803. PMID: 15983186.

(EXC4)—Wrong Outcome Or No Outcome Of Interest

1. Cimprich B, Janz NK, Northouse L, et al. Taking CHARGE: a self-management program for women following breast cancer treatment. Psychooncology. 2005 Sep;14(9):704-17. PMID: 15651055.

2. Curcio KR, Lambe C, Schneider S, et al. Evaluation of a cancer survivorship protocol: transitioning patients to survivors. Clin J Oncol Nurs. 2012 Aug;16(4):400-6. PMID: 22842691.

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4. Flood KL, Carroll MB, Le CV, et al. Polypharmacy in hospitalized older adult cancer patients: experience from a prospective, observational study of an oncology-acute care for elders unit. Am J Geriatr Pharmacother. 2009 Jun;7(3):151-8. PMID: 19616183.

5. Walsh-Burke K, Marcusen C. Self-advocacy training for cancer survivors. The Cancer Survival Toolbox. Cancer Pract. 1999 Nov-Dec;7(6):297-301. PMID: 10732527.

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7. Steinglass P, Ostroff JS, Steinglass AS. Multiple family groups for adult cancer survivors and their families: a 1-day workshop model. Fam Process. 2011 Sep;50(3):393-409. PMID: 21884077.

(EXC5)—Single Service Only-Single Need/Multiple Providers

1. Campbell KL, Van Patten CL, Neil SE, et al. Feasibility of a lifestyle intervention on body weight and serum biomarkers in breast cancer survivors with overweight and obesity. J Acad Nutr Diet. 2012 Apr;112(4):559-67. PMID: 22709706.

2. Glynne-Jones R, Chait I, Thomas SF. When and how to discharge cancer survivors in long term remission from follow-up: the effectiveness of a contract. Clin Oncol (R Coll Radiol). 1997;9(1):25-9. PMID: 9039810.

3. Grunfeld E, Levine MN, Julian JA, et al. Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. J Clin Oncol. 2006 Feb 20;24(6):848-55. PMID: 16418496.

4. Kinney CK, Rodgers DM, Nash KA, et al. Holistic healing for women with breast cancer through a mind, body, and spirit self-empowerment program. J Holist Nurs. 2003 Sep;21(3):260-79. PMID: 14528850.

5. Kwok C, Ho M. Development and evaluation of a culturally sensitive support group programme for Chinese-Australian women with breast cancer: a pilot study. Eur J Cancer Care (Engl). 2011 Nov;20(6):795-802. PMID: 21771132.

6. van Weert E, May AM, Korstjens I, et al. Cancer-related fatigue and rehabilitation: a randomized controlled multicenter trial comparing physical training combined with cognitive-behavioral therapy with physical training only and with no intervention. Phys Ther. 2010 Oct;90(10):1413-25. PMID: 20651011.

7. Waltman NL, Twiss JJ, Ott CD, et al. Testing an intervention for preventing osteoporosis in postmenopausal breast cancer survivors. J Nurs Scholarsh. 2003;35(4):333-8. PMID: 14735675.

8. Waltman NL, Twiss JJ, Ott CD, et al. The effect of weight training on bone mineral density and bone turnover in postmenopausal breast cancer survivors with bone loss: a 24-month randomized controlled trial. Osteoporos Int. 2010 Aug;21(8):1361-9. PMID: 19802506.

9. Zibecchi L, Greendale GA, Ganz PA. Comprehensive menopausal assessment: an approach to managing vasomotor and urogenital symptoms in breast cancer survivors. Oncol Nurs Forum. 2003;30(3):393-407. PMID: 12719740.

(EXC5)—Single Service Only-Single Need/Single Provider

1. Hypnosis helps reduce hot flashes in breast cancer survivors. Harv Womens Health Watch. 2009 Feb;16(6):3. PMID: 19297743.

2. Amsterdam A, Krychman ML. Sexual dysfunction in patients with gynecologic neoplasms: a retrospective pilot study. J Sex Med. 2006 Jul;3(4):646-9. PMID: 16776780.

3. Ashing-Giwa KT. Enhancing physical well-being and overall quality of life among underserved Latina-American cervical cancer survivors: feasibility study. J Cancer Surviv. 2008 Sep;2(3):215-23. PMID: 18712607.

4. Benton B, Norton C, Lindsay JO, et al. Can nurses manage gastrointestinal symptoms arising from pelvic radiation disease? Clin Oncol (R Coll Radiol). 2011 Oct;23(8):538-51. PMID: 21530194.

5. Butt CM. Hope in patients with cancer transitioning to survivorship: the mid-life directions workshop as a supportive intervention. Oncol Nurs Forum. 2012 May 1;39(3):E269-74. PMID: 22543398.

6. Heidrich SM, Brown RL, Egan JJ, et al. An individualized representational intervention to improve symptom management (IRIS) in older breast cancer survivors: three pilot studies. Oncol Nurs Forum. 2009 May;36(3):E133-43. PMID: 19403441.

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Appendix D. Evidence Tables

Evidence Table 1. Study characteristics—physician-led survivorship care models

Author, Year Trial Name	Funding Source Country If not U.S., Where	Study Design	Setting	Intervention Group(s) If Present/ Applicable	Comparator(s) If Present/ Applicable	Overall Sample Size If Present/ Applicable	Group Sample Sizes If Present/ Applicable
Cannon, 2010[1] NR	Academic U.S. NA	Prospective cohort	Teaching hospital system NA	G1: Usual care, Single provider G2: Usual care, Multiple providers	NR	314	G1: 214 G2: 100 Analyzed: G1: 214 G2: 100
Kokko, 2005[2] NR	NR Non-U.S. Finland	Parallel RCT	Other Hospital department of oncology	G1: Frequent visits and routine tests G2: Frequent visits and no routine tests G3: Infrequent visits and routine tests G4: Infrequent visits and no routine tests	NR	472	Randomized/ assigned: G1: 125 G2: 114 G3: 118 G4: 115 Analyzed: G1: 125 G2: 114 G3: 118 G4: 115
Wattchow, 2006[3]	Multiple Non-U.S. Australia	Parallel RCT	Other Multicenter (multiple hospitals)	G1: General Practioner followup G2: Surgeon followup		203	Randomized/ assigned: G1: 97 G2: 106 Analyzed: G1: 82 (12 months) G2: 88 (12 months) G1: 76 (24 months) G2: 81 (24 months)

Abbreviations: G = group; NA = not applicable; NR = not reported; RCT = randomized controlled trial; U.S. = United States.

Evidence Table 2. Study characteristics—nurse-led survivorship care models

Author, Year Trial Name	Funding Source Country If not U.S., Where	Study Design	Setting	Intervention Group(s) If Present/ Applicable	Comparator(s) If Present/ Applicable	Overall Sample Size If Present/ Applicable	Group Sample Sizes If Present/ Applicable
Gates, 2012[4] NR	NR Non-U.S. Australia	Prospective cohort	Teaching hospital system NA	G1: Nurse-led followup	G1: Healthy participants	60	Assigned: G1: 30 G2: 30 Analyzed: G1: 0 (study ongoing) G2: 0 (study ongoing)
Knowles, 2007[5] NR	Multiple Non-U.S. United Kingdom	Case series	Other Surgical outpatient department	G1: Nurse-led followup	NR	60	Assigned: G1: 60 Analyzed: G1: 50–60

Abbreviations: G = group; NA = not applicable; NR = not reported; U.S. = United States.

Evidence Table 3. Study characteristics—survivorship care models focused on SCP development

Author, Year Trial Name	Funding Source Country If Not U.S., Where	Study Design	Setting	Intervention Group(s) If Present/ Applicable	Comparator(s) If Present/ Applicable	Overall Sample Size If Present/ Applicable	Group Sample Sizes If Present/ Applicable
Curcio, 2011[6] NR	NR U.S. NA	Case series	Community center/ based NA	G1: Survivorship protocol	NR	30	Assigned: G1: 30 Analyzed: G1: 30
Grunfeld, 2011[7] NR	Multiple Non-U.S. Canada	Parallel RCT	Multiple: some services are provided are described in one setting and others in another setting, report all of the settings described and related services (note in comments) Oncology; primary care (routine followup care)	G1: Ususal care, SCP	G1: Usual care, no SCP	408	Randomized/ assigned: G1: 200 G2: 208 Analyzed: G1: 170 G2: 186
Jefford, 2011[8] NR	Foundation/ non-profit Non-U.S. Australia	Case series	Teaching hospital system NA	G1: SurvivorCare intervention	NR	10	Assigned: G1: 10 Analyzed: G1: 8–10

Abbreviations: G = group; NA = not applicable; NR = not reported; RCT = randomized controlled trial; SCP = survivorship care plan; U.S. = United States.

Evidence Table 4. Study characteristics—survivorship care model comparing group versus individual counseling

Author, Year Trial Name	Funding Source Country If Not U.S., Where	Study Design	Setting	Intervention Group(s) If Present/ Applicable	Comparator(s) If Present/ Applicable	Overall Sample Size If Present/ Applicable	Group Sample Sizes If Present/ Applicable
Naumann, 2012[9]	Programme delivery grant from the HBF, Australia NR NR	Controlled clinical trial	NR	G1: Individual-based exercise and counseling G2: Group-based exercise and counseling	Gn: Usual care	40	Randomized/ assigned: G1: 13 G2: 15 G3: 12 Analyzed: G1: 12 G2: 14 G3: 10

Abbreviations: G = group; HBF = Hospital Benefit Fund; NR = not reported.

Evidence Table 5. Intervention characteristics—physician-led survivorship care models

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Cannon, 2010[1] NR NR Patients	Inclusion criteria: • Patients who were at least 19 years of age (age of consent in Nebraska) and who had completed cancer treatment at UNMC were included. Because Nebraska has a low number of ethnic minorities and is a predominantly rural state, all racial/ethnic minorities and patients coming from rural areas were first included.	To study the association between number of followup providers among survivors of hematologic malignancies and serious medical utilization. Average duration of interaction in days/weeks/months/years (SD): study looked at 6 months CANCER CARE of data. NR	G1: Usual care with single provider (university-based oncologist or community physician [i.e., internist, family medicine physician, community oncologist]) G2: Usual care with multiple providers (university-based oncologist and community physician or community-based oncologist and either an internist or a family medicine physician)	NA	G1: Intervention component 1: university-based oncologist or community physician (i.e., internist, family medicine physician, community oncologist (face to face, phone) G2: Intervention component 1: university-based oncologisit and community physician or community-based oncologist and either an internist or a family medicine physician (face to face, phone)

Evidence Table 5. Intervention characteristics—physician-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Kokko, 2005[2] NR NR Patients	Inclusion criteria: • Female patients with localized breast cancer diagnosed in the area of Tampere University Hospital between May 1991 and December 1995 were enrolled after primary treatment. Exclusion criteria: • Patients with metastatic disease and patients participating in other adjuvant clinical trials.	Incorporate information on both costs and health outcomes to compare more intensive with less intensive interventions. Average duration of interaction in days/weeks/months/years (SD): 4.2 years NR	Routine followup visits (every third or sixth month); diagnostic examinations (routine or on clinical grounds)	Intervention component 1: Routine followup visits Average number of sessions (SD): Every three months for G1 and G2; every 6 months for G3 and G4 Average time in each session (SD): NA Intervention component 2: Diagnostic examinations Average number of sessions (SD): Blood tests every 3 months for G1, 6 months for G3, as clinically indicated for G2 and G4. Chest x-ray every 6 months for G1 and G3, as clinically indicated for G2 and G4. Liver ultrasound and	Intervention component 1: Department of Oncology (face to face) Intervention component 2: Department of Oncology (face to face) Nurse interviewed patients on every visit on use of health care services for breast cancer.

Evidence Table 5. Intervention characteristics—physician-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Kokko, 2005[2] (continued)				bone scane every second year for G1 and G3, as clinically indicated for G2 and G4. Average time in each session (SD): NA	

Evidence Table 5. Intervention characteristics—physician-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Wattchow, 2006[3] Provider led Patients	Inclusion: • Surgery for colon cancer (including rectosigmoid) with histological grade Dukes stage A, B, or C (cases of disseminated cancer were excluded). • Completion of postsurgical chemotherapy (principally Dukes Stage C patients). • Followup by GPs and surgeons available. • Able to provide informed consent. Exclusion: • Rectal tumors (current practice for rectal cancer followup requires regular sigmoidoscopy, which would not be undertaken by many GPs). • Significant polyps discovered at initial colonoscopy (or at subsequent completion colonoscopy) that indicated increased frequency of colonoscopic monitoring. • Any other condition that warranted increased intensity of surveillance with respect of colon cancer followup.	To determine whether, among these patients, the setting of followup impacts on our primary outcomes: quality of life, psychological well-being and satisfaction with care. Average duration of interaction in days/weeks/months/years (SD): NR Patients were followed for up to 24 months. N/A	Surveillance for recurrence/new cancers; symptoms	Patients expected to visit their treating clinician for followup on a quarterly basis	Intervention component 1: General practioner intervention component 2: Surgeon

Abbreviations: G = group; GPs = general practitioners; NA = not applicable; NR = not reported; SD = standard deviation; UNMC = University of Nebraska Medical Center.

Evidence Table 6. Intervention characteristics—nurse-led survivorship care models

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Gates, 2012[4] NR Nurse-led survivorship care (Draws on Pender's Revised Health Promotion Model) Patients	Inclusion criteria: • Survivor participants: Had a diagnosis of HL; received upper torso radiotherapy at any stage during their treatment history, regardless of other therapies; had to be at least 5 years postcompletion of their curative treatment for HL; had to be a new referral to the haematology late effects clinic at Peter Mac; had to be over 18 years old; had to be able to complete study requirements in English; had a sibling, partner, or significant other unaffected by a diagnosis of cancer who met eligibility criteria outlined below, and were willing to take part as a control participant.	To establish whether receiving a health promoting intervention from a specialist cancer nurse demonstrates capacity to improve HL survivors' knowledge of and motivation to adopt health-promoting behaviors. Average duration of interaction in days/weeks/months/years (SD): 6 months NR	Nurse-led consultations include an education package tailored to the individuals' health needs, screening for emotional distress, and delivery of an individualized survivorship care plan. Phone calls to reinforce intervention.	Intervention component 1: Nurse-led consultations Average number of sessions (SD): 2 Average time in each session (SD): NR Intervention component 2: Phone call to reinforce intervention. Average number of sessions (SD): 2 Average time in each session (SD): NR	Intervention component 1: Nurse (face to face) Intervention component 1: Nurse (telephone)

Evidence Table 6. Intervention characteristics—nurse-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
	Inclusion critieria (cont.): • Healthy participants: Had to be a sibling, partner or significant other of a study group HL survivor; had never been diagnosed with cancer (excluding non-melanoma skin cancers); were of comparable age (+/− five years) and gender to the study group HL survivor; had to be aged over 18 years; had to be able to complete the study requirements in English; had no co-occurring serious and/or uncontrolled illness that impacted on their functional status, including heart disease, stroke, respiratory disease, diabetes, dementia, and Alzheimer's disease.				

Evidence Table 6. Intervention characteristics—nurse-led survivorship care models (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Knowles, 2007[5] NR Nurse-led care Patients	Inclusion criteria (cont.): • All patients having undergone surgery with curative intent for a colorectal cancer primary (Dukes A, B, and C) who would be considered eligible for surgical resection in the event of disease recurrence. Exclusion criteria: • Patients with metastatic or recurrent colorectal disease. • Patients who wished to remain in traditional followup care. • Patients not deemed suitable for nurse-led followup by their surgeon/oncologist due to complications or complex comorbidities. • Patients from outside of the Lothian Area who would routinely be followed up closer to home.	Pilot study designed to assess the feasibility of a followup programme led by nurse specialists for patients with colorectal cancer Average duration of interaction in days/weeks/months/years (SD): ~12 months NR	Telephone clinic; consultant clinic; nurse specialist clinics Investigations and assessments (e.g., pathology results, symptom assessment, clinical examination, wound examination, PR exam, CEA marker, CT scan) routinely required per protocol varied per clinic interval.	Intervention component 1: Telephone clinic Average number of sessions (SD): 1 Average time in each session (SD): NR Intervention component 2: Consultant clinic Average number of sessions (SD): 1 Average time in each session (SD): NR Intervention component 3: Nurse specialist clinics Average number of sessions (SD): 3 Average time in each session (SD): 20–25 minutes	Intervention component 1: Nurse (telephone) Intervention component 2: Surgical consultant (face-to-face) Intervention component 3: Nurse (face-to-face)

Abbreviations: CEA = Carcinoembryonic antigen; CT = computed tomography; HL = Hodgkin's lymphoma; NR = not reported; PR = per rectal; SD = standard deviation.

Evidence Table 7. Intervention characteristics—survivorship care models focused on SCP development

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Curcio, 2011[6] NR NR Patients	Inclusion criteria: • Patients who had completed acute treatment for cancer within the past 2 years. Acute treatment was defined as completion of any planned surgery, chemotherapy, or radiation therapy. Survivors who remained on hormonal treatments for their cancer were considered to have completed their acute treatment and were included. Survivors within 2 years of completing their acute treatment also were included. An additional inclusion criterion was being older than 18 years. Exclusion criteria: • Having evidence of metastatic disease; receiving hospice services; and being unable to read, write, or speak English.	To improve cancer survivors' knowledge about their disease and decrease anxiety. Average duration of interaction in days/weeks/months/years (SD): 1 month NR	G1: Survivorship protocal (i.e., formalized mechanism to review IOM recommendations with the patient) visit in which an individualized SCP (developed as a collaborative effort by the nurse practitioner, medical oncologist, and registered nurses using the generic ASCO template) was reviewed with the patient and any questions were answered; a followup phone call to answer any remaining questions (and assess their anxiety and knowledge).	Intervention component 1: Survivorship visit including review of individualized care plan Average number of sessions (SD): 1 Average time in each session (SD): 58.8 minutes (12.5) Intervention component 2: Phone call Average number of sessions (SD): 1 Average time in each session: NR	Intervention component 1: nurse practitioner (face to face) Intervention component 2: nurse practitioner (telephone)

Evidence Table 7. Intervention characteristics—survivorship care models focused on SCP development (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Grunfeld, 2011[7] NR SCP Intervention component 1: Patients, PCPs also receive the patient's SCP. Intervention component 2: Patients	Inclusion criteria: • Women with early-stage breast cancer who completed primary treatment at least 3 months previously, except for continued use of tamoxifen or an aromatase inhibitor, and who were without recurrent or new primary cancer. Exclusion criteria: • Patients were excluded if they were still experiencing complications of primary treatment, did not have a PCP to provide care, were previously enrolled on a study requiring oncology followup, were actively followed up for another primary cancer, or had a PCP who already had a patient enrolled on the trial (to avoid contamination).	To determine if an SCP for breast cancer survivors improves patient-reported outcomes Average duration of interaction in days/weeks/months/years (SD): 2 years (although only results up to the 12-month visit were reported). NR	A comprehensive SCP that consisted of the prescribed elements, including a personalized treatment summary, a patient version of the Canadian national followup guideline, a summary table of the guideline that served as a reminder system, and a resource kit tailored to the patient's needs on available supportive care resources. These documents were compiled in a binder and were reviewed with the patient during a 30-minute educational session with a nurse, who also made an explicit statement that followup care was now the responsibility of the PCP and that access to the oncologist was available when needed. These documents were also sent to the patient's PCP together with the full followup guideline, a user-friendly summary version, and a reminder table.	Intervention component 1: SCP binder delivery and educational session Average number of sessions (SD): 1 Average time in each session (SD): 30 minutes Intervention component 2: Routine followup transferred to PCP	Intervention component 1: nurse (face to face) Intervention component 2: PCP (face to face)

Evidence Table 7. Intervention characteristics—survivorship care models focused on SCP development (continued)

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/ Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Jefford, 2011[8] NR NR Patients, although support people are encouraged to attend intervention component 1.	Inclusion criteria: • Eligible survivors were (a) diagnosed with CRC (stages I–III), (b) completing primary treatment with curative intent (surgery, chemotherapy, radiotherapy, or combination) or had completed primary treatment with curative intent within the past 12 months, (c) older than 18 years, and (d) able to speak sufficient English to complete questionnaires and provide informed consent. Exclusion criteria: • Patients had severe cognitive or psychological difficulties, as determined by the treating clinician.	This study aimed to develop and pilot test an innovative supportive care program for people with potentially curative CRC. Average duration of interaction in days/weeks/months/years (SD): ~7 weeks for intervention components 1 and 2. NR	Provision of information—DVD, information booklet, question prompt list (QPL); an individualized SCP for the survivor, their GP, and oncology specialists; A face-to-face, nurse-led end-of-treatment session; 3 followup telephone calls.	Intervention component 1: End-of-treatment consultation Average number of sessions (SD): 1 Average time in each session (SD): 1 hour Intervention component 2: followup telephone calls Average number of sessions (SD): 3 Average time in each session (SD): 10 minutes	Intervention component 1: Nurse (supposed to be face to face, but half were over the phone) Intervention component 2: Nurse (telelphone)

Abbreviations: ASCO = American Society of Clinical Oncology; CRC = colorectal cancer; DVD = optical disc storage format; G = group; IOM = Institute of Medicine; NR = not reported; PCP = primary care physician; QPL = question prompt list; SCP = survivorship care plan; SD = standard deviation.

Evidence Table 8. Intervention characteristics—survivorship care model comparing individual versus group counseling

Author, Year Trial Name Type of Survivorship Model, if Defined Recipient of Intervention Component	Inclusion/Exclusion Criteria	Goal of Intervention Intervention Duration Cointerventions	Components of Survivorship Care	Intensity of Intervention	Delivery Agent and Mode of Delivery
Naumann, 2012[9] A review of literature provided compelling evidence that group pyschotherapy and group exercise improve quality of life of cancer survivors, possessing unique advantages over individual interventions by providing additional opportunity for social support, social comparision, and modeling. Patients	Inclusion criteria: • Women with confirmed stages I–III breast cancer, aged 35–70 years, sufficiently fluent in English, and not meeting current American College of Sports Medicine guidelines for adequate physical activity (<150 minutes per week). Exclusion criteria: • Acute or chronic bone, join, or muscular abnormalities that would compromise patient's ability to participate in exercise; failure of Physical Activity Readiness Questionnaire; presence of metastatic disease.	To assess the feasibility of a 9-week individual- or group-based exercise and counselling program and to examine if group-based intervenion is as effective in improving the quality of life of breast cancer survivors as an individual-based intervenion. Average duration of interaction in days/weeks/months/years (SD): 9 weeks NA	G1: Exercise training sessions (combination of cardiovascular training [cycle, cross-training, brisk walking], strength training, hydrotherapy, core training, patient-specific rehabilitation, flexibility) and individual counseling (client-centered approach based on individual needs) G2: Exercise training sessions (cardiovascular training [cycle, cross-training, brisk walking], strength training [weight training in gymnasium, pump class], core training [floor, Pilates], hydrotherapy, flexibility) and group counseling (in groups of 6 to 8 women).	Intervention component 1: Exercise training Average number of sessions (SD): 27 Average time in each session (SD): 45 to 60 minutes per exercise training session for G1 and G2 Intervention component 2: Counseling (individual for G1, group for G2) Average number of sessions (SD): 9 for G1 and G2 Average time in each session: 1 hour for G1 and G2	Intervention component 1: Accredited exercise physiologist (G1 and G2) Intervention component 2: Accredited counselor (G1 and G2)

Abbreviations: G = group; NA = not applicable; SD = standard deviation.

Evidence Table 9. Patient characteristics

Type of Survivorship Intervention	Author and Year	Cancer Types(s) & Pt Numbers (%)	Stage of Disease at Diagnosis	Time Since Completion of Active Treatment	Baseline Age Mean (Range)	Baseline % Female
Physician-Led Survivorship Care Models	Cannon, 2010[70]	Leukemia: 54 (17.2) Lymphoma: 234 (74.5) Myeloma: 26 (8.3)	NA	Single physician group: median 47 months. Multiple physician group: median 38 months	Single provider: 59 (22–86); multiple providers: 55 (19–79)	50.30%
	Kokko, 2005[69]	Breast cancer: 472 (100.0)	Localized disease after primary treatment: 472 (100.0)	NR, apparently shortly after active treatment	Median 56.8–60.5, depending on study arm	100.00%
	Wattchow, 2006[71]	Colon cancer: 203 (100.0)	Dukes stages: A: 47 (23.2) B: 96 (47.3) C: 60 (29.6)	NR	NR	Overall: 42.4% G1: 38.1% G2: 46.2%
Nurse-Led Survivorship Care Models	Gates, 2012[73]	Hodgkin lymphoma (HL): 30 (100.0)	N/A	At least 5 years	Median 44 (24–72)	40.00%
	Knowles, 2007[72]	Rectal/rectosigmoid cancer:19 (31.7) Colon cancer: 41 (68.3)	Dukes A: 11 (18.3) Dukes B: 26 (43.3) Dukes C1: 18 (30.0) Dukes C2: 5 (8.3)	Telephone call 2–3 weeks following surgery; first visit 4 months following surgery	67.3 (29–94)	48.30%

Evidence Table 9. Patient characteristics (continued)

Type of Survivorship Intervention	Author and Year	Cancer Types(s) & Pt Numbers (%)	Stage of Disease at Diagnosis	Time Since Completion of Active Treatment	Baseline Age Mean (Range)	Baseline % Female
Survivorship Care Models Focused on SCP Development	Curcio, 2011[74]	Breast: 16 (53.3) Hematologic: 8 (26.7) Lung: 3 (10.0) Gastrointestinal: 3 (10.0)	Ductal carcinoma in situ: 3 (10.0) Stage I: 4 (13.3) Stage II: 14 (46.7) Stage III: 9 (30.0)	Within 2 years	64 (30–83)	83.30%
	Grunfeld, 2011[75]	Breast cancer: 408 (100.0)	Early stage: 408 (100%)	At least 3 months	61.7 no SCP; 61.2 SCP	100.00%
	Jefford, 2011[47]	Colorectal cancer: 10 (100.0)	Stage 1: 1 (10.0) State 2: 1 (10.0) Stage 3A: 3 (30.0) Stage 3B: 3 (30.0) Stage 3C: 2 (20.0)	Within 2 weeks	55 (35–71)	50.0%
Survivorship Care Model Comparing Group vs. Individuals Counseling	Naumann, 2012[48]	Breast: 36 (100%)	NR	Within 12 months	NR	100%

Abbreviations: HL = Hodgkin lymphoma; NA = not applicable; NR = not reported; Pt = patient; SCP = survivorship care plan; vs. = versus.

Evidence Table 10. Outcomes

Type of Survivorship Intervention	Author and Year	Type of Survivorship Intervention	Average Intervention Duration	Outcomes Assessed
Physician-Led Survivorship Care Models	Cannon, 2010[70]	Comparison of usual care with single vs. multiple providers	6 months	QOL-MOS short form 12 (6 months); patient satisfaction—PSQ-18 (6 months)
	Kokko, 2005[69]	Comparison of visit frequency and use of diagnostic tests	4.2 years	Disease free time; overall survival
	Wattchow, 2006[71]	Physician led	Patients expected to visit their treating clinician for followup on a quarterly basis	Quality of life, depression, and anxiety at 12 and 24 months; satisfaction at 24 months; number or recurrences and all-cause deaths at 24 months; resource utilization at 24 months
Nurse-Led Survivorship Care Models	Gates, 2012[73]	Nurse led followup	6 months	Perception of health—General Health Index (~2 weeks after each face-to-face, nurse-led consultation and again ~2 months after second phone call/last intervention component); engagement in health-promoting activities—Health Promoting Lifestyle Profile II (~2 weeks after each face-to-face, nurse-led consultation and again ~2 months after second phone call/last intervention component)
	Knowles, 2007[72]	Nurse-led followup	~12 months	Patient recurrence; quality of life—EORTC QLQ-C30 and EORTC QLC-CR38 (measured at each face-to-face visit); satisfaction with intervention—adapted rheumatology patient population questionnaire (measured at face-to-face 12-month visit)

Evidence Table 10. Outcomes (continued)

Type of Survivorship Intervention	Author and Year	Type of Survivorship Intervention	Average Intervention Duration	Outcomes Assessed
Survivorship Care Models Focused on SCP Development	Curcio, 2012[74]	Survivorship protocol	1 month	Improve cancer survivors' knowledge about cancer (1 month); decrease cancer survivors' anxiety—GAD-7 (1 month); fidelity to evidence-based followup (1 month); patient satisfaction—survey (immediately following the survivorship visit protocol)
	Grunfeld, 2011[75]	SCP	2 years (although only results up to the 12-month visit were reported)	Cancer-related distress—IES (questionnaires completed at 3, 6, 12, 18, and 24 months but only 3, 6, 12 reported); general psychological distress—POMS (questionnaires completed at 3, 6, 12, 18, and 24 months but only 3, 6, 12 reported); quality of life—SF-36 (questionnaires completed at 3, 6, 12, 18, and 24 months but only 3, 6, 12 reported); patient satisfaction—PSQ (questionnaires completed at 3, 6, 12, 18, and 24 months but only 3, 6, 12 reported); continuity/coordination of care—CCCQ (questionnaires completed at 3, 6, 12, 18, and 24 months but only 3, 6, 12 reported)

Evidence Table 10. Outcomes (continued)

Type of Survivorship Intervention	Author and Year	Type of Survivorship Intervention	Average Intervention Duration	Outcomes Assessed
Survivorship Care Models Focused on SCP Development	Jefford, 2011[47]	SurvivorCare intervention	~7 weeks	Unmet needs—CaSUN (1 week); Psychological distress - BSI-18 (1 week); quality of life—QLQ-C30 (1 week); satisfaction with intervention (unspecified)
Survivorship Care Model Comparing Group vs. Individuals Counseling	Naumann, 2012[48]	Individual- vs. group-based exercise and counseling	9 weeks	Global QOL—FACT-B QOL Scale (measured at baseline and intervention completion); QOL Subscales: 1. Physical well-being (measured at baseline and intervention completion); 2. Social well-being (measured at baseline and intervention completion); 3. Emotional well-being (measured at baseline and intervention completion); 4. Functional well-being (measured at baseline and intervention completion); feasibility measurements: recruitment, retention, session attendance, adherence to exercise, adherence to counseling programs

Abbreviations: BSI-18 = Brief Symptom Inventory 18; CaSUN = Cancer Survivors' Unmet Needs measure; CCCQ =Clinical Cultural Competency Questionnaire ; EORTC = European Organization for Research & Treatment of Cancer; FACT-B = Functional Assessment of Cancer Therapy—Breast FACT-B; GAD-7 = General Anxiety Disorder Assessment-7; IES = Impact of Event Scale; POMS = Profile of Mood States; PSQ-18 = Patient Satisfaction Questionnaire-18; QLQ-C38 Cancer Specific Quality of Life Questionnaire; QLQ-C30 = Cancer Specific Quality of Life Questionnaire; QOL = quality of life; QOL-MOS = quality of life-medical outcome study; SCP = survivorship care plan; SF-36 = Short Form (36) Health Survey ; vs. = versus.

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Appendix E. Glossary of Terms

1. Cancer survivor: An individual who has completed the majority or all of their active treatment for cancer (i.e., treatment with curative intent).
2. Survivorship care: A health care service or combination of services for cancer survivors that has one or more of these four components as defined by the IOM Committee on Cancer Survivorship: Improving Care and Quality of Life, Institute of Medicine and National Research Council. (From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: The National Academies Press, 2005, page 3):
    a. Prevention of recurrent and new cancers and of other late effects; promotion of healthy behaviors and appropriate screening procedures
    b. Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects
    c. Intervention for consequences of cancer and its treatment, for example, physical consequences such as medical problems or symptoms, including pain and fatigue, psychological distress experienced by cancer survivors and their caregivers, and social and spiritual
    d. Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met through clear communication and implementation of survivorship care plans
3. Survivorship Research: Cancer survivorship research encompasses the physical, psychosocial, and economic sequelae of cancer diagnosis and its treatment among both pediatric and adult survivors of cancer. It also includes within its domain issues related to health care delivery, access, and followup care, as they relate to survivors. Survivorship research focuses on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase. It seeks to both prevent and control adverse cancer diagnosis and treatment-related outcomes such as late effects of treatment, second cancers, and poor quality of life, to provide a knowledge base regarding optimal followup care and surveillance of cancers, and to optimize health after cancer treatment. (http://dccps.nci.nih.gov/ocs/definitions.html)
4. Cancer Survivorship Program (ACS): "comprehensive set of services provided by multidisciplinary groups working together to ensure effective medical care, education and emotional support."
5. Models of survivorship care: The construct behind the term "model" relates to the cohesiveness of a program which infers more than one service. In the Technical Brief, we describe various types of models found in the literature.
    a. Consultative model: the patient is primarily seen by primary care or survivorship care team, but periodically or on a as needed basis refers to the oncology team for services.
    b. Multidisciplinary clinic: specialty (i.e., oncology) clinics coordinate with primary care and other medical service clinics to provide survivorship care
    c. Integrated care model: each member of the patients' survivorship care experience is communicating with each other and with the patient
    d. Transition to primary care: the patient moves from predominantly oncology team care during active treatment to primary care for survivorship services
    e. Shared-care model: patient care arrangement where the primary care team and the oncology team both provide survivorship services to the patient based on the patient's medical needs
    f. Survivor care plan: medically guided instructions for patient care during the survivorship stage based on an assessment of patient needs
    g. Patient navigator: a lay/peer health partner who serves as a resource to the patient about their survivorship care and a liaison between the patient and their medical team and services